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**Factors contributing to paediatric tube feeding dependence in New Zealand:
The Speech-language therapy perspective.**

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Abstract

Tube feeding dependency can have serious repercussions for children and their families. Most research relates to intervention programmes for tube withdrawal/weaning onto oral feeding. However, there is limited research into factors contributing to tube feeding dependency. Researchers have found failed or slow weaning/transitioning from tube to oral feeding is more likely after the age of five. In New Zealand the highest number of children who remain tube dependent but could transition to oral feeding are over five years of age. Speech–language therapists (SLTs) are one of the main professions involved in managing these children.

This two-phase study aimed to determine the SLTs' perspective of factors contributing to feeding tube dependency in children. This study used a mixed method approach. Forty-three SLTs participated in an online survey and ten of these participants were interviewed.

Two interlinking themes were found as contributing factors to tube feeding dependency in children. They were: (1) *Medicalisation of tube fed children in infancy as a root cause of tube feeding dependency*. Sub themes included the following: Medical emphasis on weight gain; parents and caregivers influence whether a child remains tube dependent; parents giving misleading information to maintain tube feeding and prolonged NGT feeding. (2) *Fragmentation of the tube fed child's continuity of care*. Sub-themes include the following: The need for planning tube withdrawal at the time of insertion, insufficient clinical time, funding issues, the need for intensive service at the time of tube weaning, clinician confidence in the education setting and the normalisation of tube feeding by school age. These themes and sub-themes influence tube feeding dependency in New Zealand, according to the perspective of SLTs.

This research highlights the need for further exploration of these factors when the tube is first inserted to prevent dependency and allow the transitioning of children to oral foods as early as possible.

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Chapter One- Introduction

Tube feeding, the act of delivering nutrition through a tube is necessary when children are unable or unwilling to get enough nutrition orally to maintain adequate weight gain and growth (Gauderer, 2002). This chapter will introduce the topic of tube feeding, and the difficulties associated with the practice that may lead to tube feeding dependency in children. The role of speech-language therapists (SLTs) and their perspectives on factors contributing to tube feeding dependency will also be discussed.

What is tube feeding?

Tube feeding, also known as enteral or gavage feeding is used to increase nutritional intake in humans (Phillips, 2006). Adults and children who cannot sustain nutrition orally require food to be given through an infusion of formula directly into the stomach (Thorne, Radford & McCormick, 1997). The two most commonly used methods of enteral feeding are nasogastric tubes (NGTs), (a tube that is inserted through the nose and oesophagus and then into the stomach) and gastrostomy or percutaneous enteral gastrostomy (PEG) tubes (a surgically created external opening is placed in the stomach wall through which a catheter is implanted) (Pederson, Parsons & Dewey, 2004). NGTs may be recommended to increase the weight or to increase the nutritional status of infants who aspirate or do not have the energy to get adequate nutrition through oral feedings. This type of tube feeding is recommended for short-term non-oral intake. If a child cannot get his/her nutritional needs orally for three to four months or more a PEG tube is considered (Mason, Harris, & Blissett, 2005).

Potential risk of over utilisation

Due to medical advances, more infants that are premature and those with other medical complications are surviving and often require tube feeding. Although we have the means to assist these children the potential negative side effects and complications are increasing often preventing or delaying transition to oral feeding (Mason et al., 2005). After a tube is inserted an important final goal should be to return the patient to oral intake as soon as possible, as eating and drinking is usually associated with pleasure and provides much needed social interaction (Gauderer, 2002).

Problems associated with tube feeding in children

Children with otherwise normal oral motor skills may end up being tube fed if their feeding development has been interrupted due to a medical condition. These children are often tube fed to improve nutritional status in the short term. However, these children may experience negative

associations with oral feeding (Mason et al., 2005). For example, some negative associations are fatigue during feeding, vomiting, or being unable to control food and fluid in the mouth. These negative associations may cause problems transitioning from tube to oral feeding.

Children's reactions to oral feeding may also cause parental stress, decreased parent child interaction at mealtimes and undesired behaviours, such as fighting, crying, gagging, coughing and vomiting (Davis, Bruce, Cocjin, Mousa & Hyman, 2010; Greer, Gulotta, Masler, & Laud, 2008; Heyman et al., 2004; Mason et al., 2005). However, some may not experience these difficulties. Douglas and Bryon (1996) reported that it was unclear why some tube fed children have difficulty transferring to oral feeding when the tube is no longer required.

One reason for some children's difficulties transitioning from tube to oral feeding may be linked to the duration and time of tube placement. Infants with complex medical conditions, particularly premature infants, may have feeding difficulties that persist beyond the first year of life, especially if tube feeding is prolonged (Cerro, Zeunart, Simmer and Daniels, 2002; Hawdon, Beauregard, Slattery & Kennedy, 2000; Mason et al., 2005). The reason for these persistent difficulties is that prolonged tube feeding in the first year of life may disrupt feeding development. Tube feeding is life saving and an excellent short-term solution to sustaining nutrition and growth. However, if oral feeding is compromised or delayed, this can have negative effects on feeding development and lead to tube feeding dependency.

Tube feeding dependency in children

Tube dependency is defined as an unintended dependence on long-term tube feeding in infants and young children (Dunitz-Scheer et al., 2009). These are infants and children who remain tube fed although their medical condition and developmental potential would allow them to transition to eating and drinking by mouth (Dunitz-Scheer et al., 2011). These children are the focus of this study.

At present, there are over 600 tube fed children in New Zealand (Jelleyman, 2013). One out of four of these tube fed children are tube dependent. The majority of these children are over five years of age.

The Speech-language therapists'

In multidisciplinary paediatric feeding teams the SLTs typically take the lead in managing swallowing and feeding difficulties (Dodrill, 2015). A recent report by paediatricians to the Ministry of Health identified SLTs as having a major role in the management of children who are tube fed (Jelleyman, 2013).

Aim of study

The aim of this study is to identify factors that contribute to paediatric tube dependency in New Zealand from the speech–language therapists’ perspective. The SLTs’ perspective is important because of their role in managing tube fed children. Their perspectives about this phenomenon of tube feeding dependency have yet to be explored.

Chapter One has provided an overview of the key constructs and aim of this study. Chapter Two begins with a synopsis of findings in the literature that contribute to tube feeding dependency. This is followed by the current interventions to transition children from tube to oral feeding. The factors influencing the success of these interventions will also be explored. Chapter Three outlines the study design and methodology underpinning the research, alongside the methods for data collection and analysis. Due to the mixed methods design the results will be presented in two chapters. Chapter Four will present the results from the quantitative phase of the study while key themes from the qualitative phase of the study will be presented in Chapter Five. The findings from both phases are integrated and discussed in relation to the literature in Chapter Six. Chapter Six also presents a summary of the limitations of the study along with the conclusions and possible directions for future research.

Chapter Two-Literature Review

The aim of this literature review is to outline and discuss factors contributing to tube feeding dependency and preventing tube fed children transitioning to oral feeding. Current interventions for weaning children from tubes are also discussed.

Factors contributing to tube feeding dependency, preventing transition to oral feeding

Studies have shown that parent- child interaction, parental anxiety, gastroesophageal reflux and vomiting, and oral sensory defensiveness prove challenging for the child trying to transition from tube to oral feeding (Arvedson, 1997; Gahagan, 2012; Kerwin, 1999; Owen et al., 2012; Slaughter & Bryant, 2004; Wilken, 2012). These difficulties will now be discussed in more detail.

Parent-Child Interaction

Tube feeding can disrupt the feeding relationship between mother and child ultimately affecting the parent-child interaction. Wilken (2012) in a recent meta-analysis suggested that feeding a child orally is not only an important aspect of mothering but also a key element for the development of motherhood identity. Based on the findings from his meta-analysis, Wilken proposed that tube feeding might cause psychological stress for the mother and feelings of maternal guilt when she is unable to provide a nurturing experience, causing a struggle to form a bond with the infant.

The feeding relationship between a mother and child is a learned experience. This relationship forms the basis for the child not only for their feeding ability but also for their self-regulation and attachment to the mother (Gahagan, 2012; Kerwin, 1999; Owen et al., 2012). Feeding development will be discussed next followed by the consequence of disruption to the feeding relationship.

Typical feeding development

For the feeding process to be successful, the infant needs to communicate with the mother that they are hungry. The mother must read these feeding cues appropriately. This process is complex and easily disrupted. Slaughter and Bryant (2004) commented that a foetus is fed without having to communicate about their hunger, but a new born experiences a radical change from life in the womb; a parent's responsibility is to observe this new form of communication, decipher what the baby is trying to say, and then fulfil the need being expressed. When the parent has solved the riddle and supplied the need, the baby feels understood, comforted, safe, and secure. . There are three stages in feeding development occurring in the first two years of life; they are homeostasis, attachment, and separation/individuation (Chatoor, Schaefer, Dickson, & Egan, 1984). Chatoor et al.

(1984) stated that the evolution of positive eating habits requires the infant and mother to maintain an active state of give and take (reciprocity) in each stage of feeding development.

The three stages of feeding development

Feeding development is described in three stages: Homeostasis, followed by attachment and then finally individuation. The first stage of feeding development is homeostasis. During this stage the infant cannot self-regulate for the first two months of life. In order to interact with the world the new born has to stabilise biologic functions and their nervous system (Arvedson, 1997). At this stage the infant feeds reflexively and requires their caregiver, usually their mother, to read their cues effectively to know when to feed the baby. If the mother is unable to determine if the infant is hungry the baby will become upset and need calming before feeding can begin. Arvedson reported that if this continues and the mother misunderstands the infant's cues indicating hunger true engagement between mother and child will not occur. As a result, the mother's confidence in feeding their child may decrease, negatively affecting the next stage of feeding development, attachment (Arvedson).

The second stage, the attachment stage begins as the infant starts to change from a reflexive feeder to a developing feeder (McCurtin, 2006). The infant enters into this stage of attachment with the aim of establishing specific interactional patterns with their caregiver (Arvedson, 1997, Satter, 1990). Caregivers encourage this attachment by maintaining reciprocity by keeping regular meal, sleep times, and monitoring developmental changes. An example of becoming a developing feeder is the initiation of spoon feeding at around four to six months (Arvedson, 1997). However, if the infant and parent do not experience true engagement during this attachment stage, the infant is unlikely to find feeding pleasurable. Other feeding difficulties can include; reduced appetite, vomiting, and rumination.

The quality of this engagement between mother and child may be affected by the separation of the infant and mother due to illness and/or hospitalisation of the infant during the homeostasis and attachment stages. These illnesses or hospitalisations often lead to the arrest of feeding development, which is frequently the case for tube dependent infants (Franklin & Rodger, 2003). If true engagement does not occur in the attachment stage, this will directly affect the last stage of feeding development, the individuation/separation stage.

The individuation stage, the final stage in feeding development (generally from six to thirty – six months of age) is when the infant separates from their mother/attachment figure and wants to feed themselves and wants to explore foods in their environment with their hands and mouths. During the period of individuation, children may experience neophobia, the fear of new things. In relation to feeding, this could be the fear of new foods or familiar foods that are presented

differently, for example a broken biscuit. Franklin and Rodger (2003) explained that all children progress through food neophobia and sensory defensive tendencies (dislike of touching certain textures), which may affect their future food choices and food preferences. However, inappropriate confrontation of these tendencies can result in a feeding disorder and tube feeding dependency. For example, negative experiences with feeding and/or disengagement of the main carer with feeding (Franklin & Rodger, 2003).

Tube feeding and maternal grief

A consequence of this separation of the mother and child can lead to the following issues. Mothers can experience grief over the inability to feed their tube fed child, which can lead to anxiety about oral feeding in the future and the consequent behaviours that affect the tube fed child to be able to transition to oral feeding.

In their qualitative study of mothers' experiences of looking after their child with feeding difficulties including tube feeding, Hewetson and Singh (2009) identified a major theme of 'losing the mother dream'. In their study, mothers described a strong, universal feeling of the loss of their ideals of motherhood, which extended further to the loss of the opportunity to bond with their children. "For most of the mothers, feeding became a tiring and overwhelming task which challenged their emotional capacity to accept the loss of what they had expected to be a bonding opportunity" (Hewetson & Singh, 2009 pg. 325).

Parental anxiety and subsequent mealtime behaviour towards their child:

According to Douglas and Bryon (1996), parental behaviours towards their child's feeding may include over protectiveness, high anxiety, permissiveness, and inconsistent daily routines. Dunitz-Scheer et al. (2011) reported that parents might become fixated on the ability of their child to feed independently, which may result in forced feeding patterns in order to obtain as much oral nutrition as possible.

In contrast, Dunitz-Scheer et al. (2011) reported that some parents with tube dependent children often became focused on tube feeding, engaging in constant preparations for the next tube feed. Dunitz-Scheer et al. reported that parents favoured tube feeding as they had complete control over their child's nutrition. This is due to increased caregiver anxiety resulting from recurrent hospitalisations of their child. This may result in the child having no or minimal experience tasting or touching food. Both these situations do not support reciprocity in the feeding relationship (Dovey and Martin, 2011; Wright, 2013b; Wright, Smith and Morrison, 2011). In addition to the emotional challenges described above, the time feeding has an effect on parent-child bonding. Research done by Heyman, Harmanz, Acree et al. (2004) found that maternal caregivers could spend over 8 hours a

day directly managing a tube fed child. This time spent on routine care of tube feeding and maintaining the tube detracts from developmental activities involving their child and other family activities. In other words, such activities turn the parent into a carer. Pederson et al. (2004) reported that the extensive time commitment experienced by parents for even basic tube care led to an extreme degree of stress that was greater than parents of children with other chronic illnesses. The impact on family mealtime interaction is described next.

Dunitz-Scheer, Scheer and Tappauf (2007) believe that the first two years of a child's life is the critical time to encourage food exploration and establish independent oral feeding. Children may display increased resistance to trying new foods as they get older if they have previously had limited exploration of food. This is mainly due to reduced reciprocity with the parent, and rigid tube feeding schedules (Illingworth and Lister, 1964).

Parental anxiety about their child's feeding can result in the child experiencing limited exploration of food in the first two years of life. The first two years is a critical time for feeding development and if disrupted is a factor contributing to difficulties transitioning from tube to oral feeding. This can lead to appetite dysregulation, a factor contributing to tube dependency.

Appetite dysregulation, reflux, and vomiting

To encourage appetite regulation, Schauster and Dwyer (1996) and Jordan (2012) recommended normalising tube feeding schedules to mimic regular infant and child mealtimes to help transition to oral feeding. Feeding a healthy infant is based on the infant's ability to interpret hunger and satiety cues, then to communicate those feelings to the caregiver. Tube dependent children often do not understand the link between food and their well-being as hunger is externally driven by their tube feeds (Dovey & Martin, 2011). The first step is to normalise tube-feeding timing to resemble regular mealtimes. For example, three larger and two smaller bolus tube feedings could be administered at the usual times for meals and snacks (Schauster & Dwyer, 1996). In addition, Jordan (2012) suggested that, treatment approaches to feeding disorders should provide a secure base for the infant to explore food. This secure base enables the child to harness their curiosity about the world, explore food and feeding experiences by separating from the parent, but knowing when to return to feel secure. This encourages autonomy, emotional development, and helps intuitive parenting (Von Hofaker & Papoušek (1998).

In contrast to this idea of scheduling feeds and encouraging exploration, Wright (2013a) reported that tube feeds should be reduced once a child has reached an appropriate developmental stage. She reported that this is appropriate to support the idea of the child establishing a link between hunger and eating orally even if the child shows no interest in food.

Appetite dysregulation affects the child's hunger drive and motivation for oral feeding. Another factor that contributes to tube feeding dependency is the effect of gastroesophageal reflux

and vomiting. Gastroesophageal reflux disease (GORD) is the return of the stomach contents into the oesophagus and possibly the pharynx (Strudwick, 2003). Strudwick reported that the symptoms of GORD and/or GOR include vomiting, outright food refusal, refusal to resume feeding after winding, screaming in pain during feeding, arching of the back when feeding, and feeding better when asleep, or less alert. Other symptoms reported are gagging, uncoordinated oral-motor patterns, and hoarseness/wheeziness and signs aspiration, including coughing, choking, apnoea, and persistent phlegm. Douglas and Bryon (1996) interviewed the families of 201 participants about factors that contributed to their child's chronic feeding disorder. Seventy percent of participants reported frequent and long lasting vomiting in the first year of their children's life (Douglas & Byron, 1996). Dellert, Hyams, Treem et al. (1993) and Hall (2001) reported that infants with GORD resisted oral feeding and have oral hypersensitivity that decreased the child's desire to explore food.

Vomiting, as well as increasing negative associations with oral feeding, also influences the delivery of tube feeding. To ensure appropriate nutrition, tube feeds are given continuously instead of as a bolus (representing a mealtime volume). For example, the tube delivers two millilitres of nutrition (Pediasure®, Nutriini®) every five minutes, affecting appetite (Schauster & Dwyer, 1996). The type of tube the child has, as discussed next, may also exacerbate vomiting and GOR.

Type of feeding tube

Research has shown that NGTs can cause GOR, vomiting and inflammation of the oesophagus and sensory changes to the pharynx (Mason et al., 2005; Meyer Palmer & Heyman, 1993; Skuse, 1993). However, insertion of a PEG tube can decrease the frequency of reflux and vomiting, as well as parental stress (Avitsland, Birketvedt, Bjornland & Emblem, 2013; Lee & Shiun, 2011; Pemberton, Frankfurter, Bailey, Jones & Walton, 2011).

Despite these positive outcomes, PEG tube placement is not without its difficulties, particularly with stoma care (opening in the stomach) including leakage, skin irritation, catheter migration, dislodgement and pain (Gauderer, 2012). It appears that the type of feeding tube used can cause or exacerbate negative experiences for the child. These aversive incidents may prevent the child transitioning to oral feeding. However, maintenance of these negative experiences could also be due to the duration and time of tube placement, which is discussed next.

Another reason for tube feeding dependency may be linked to the duration and time of tube placement. If transition from reflexive to voluntary feeding is disrupted in, the attachment stage of feeding development it may result in the child not developing independent feeding skills. This is particularly true if oral feeding is disrupted when solid foods are introduced at around 6-8 months of age, the individuation stage. According to Schauster and Dwyer (1996) when this developmental

window closes, independent oral feeding will be compromised. The consequence of this is often difficulty transitioning from being tube fed to oral feeding, as the child gets older.

Similarly Mason et al. (2005) suggested in their review, that transitioning infants from feeding tubes to oral feeding may be easier when feeding is still reflexive (0-4 months). This is due to children wanting more control over feeding in the individuation stage. Consequently, older tube fed children whose feeding development is disrupted have a higher chance of experiencing oral sensory defensiveness, causing significant barriers to transitioning to oral feeding.

Oral Sensory Defensiveness

Another difficulty concerning tube dependency and difficulty transitioning to oral feeding for children is oral sensory defensiveness. Children with oral sensory defensiveness often demonstrate an emotional response to sensory input to the oral facial region, such as gagging when food approaches or touches their lips (Arvedson & Brodsky, 2002). These children will usually avoid food differing in textures and tastes; and/or avoid mouthing toys and teeth brushing. This oral defensiveness affects their ability to accept foods orally, and can severely limit children consuming the volumes of food needed to sustain nutrition. Scarborough et al. (2006) observed gagging and distress behaviours to touch on the body. They found that children with persistent feeding difficulties showed overt gagging in response to being touched on the face and body, compared to the comparison group, consisting of children with unremarkable medical histories. The experimental group had different medical backgrounds but were tube fed during their reflexive feeding period (0-4 months) and displayed gagging and behaviour state changes to touch (Scarborough et al., 2006).

Douglas and Bryon (1996) found that of the 82 families surveyed in their study of children with behavioural feeding difficulties, including tube fed children, that one third of the children never sucked their fingers or thumbs. One quarter refused to have their teeth brushed and 22% were reluctant to explore toys in their mouths. This may have a significant impact on the child's feeding development as the gag reflex is elicited in infants at the anterior two thirds of the tongue. Whereas, by nine months of age, this reflex should have moved back to the posterior third of the tongue (Fraker, Fishbein, Cox & Walbert, 2007); if infants are tube fed they may not be able to mouth fingers and non-food items during sensitive periods of the feeding development process described previously, this may severely affect transition to oral feeding (Mason et al., 2005).

Mason et al. (2005) reinforced the significance of infants and children who are tube fed not accepting food into their mouths. They reported the impact of tube feeding in infancy on the development of normal eating and drinking skills, reporting that the child will not make the

connection between hunger satiety and eating orally. Therefore, even trying to reduce tube feeds to stimulate appetite will not lead to oral intake.

Interventions for transitioning from tube to oral feeding-“Tube weaning”

Research done particularly in the last two decades on transitioning children from tube to oral feeding or “tube weaning” has looked at single discipline behavioural interventions; focused on increasing appropriate feeding behaviours and decreasing maladaptive feeding/eating behaviours (Kerwin, 1999; Sharp, Jaquess, Morton & Herzinger, 2010). A systematic review of treatments for severe feeding difficulties by Kerwin (1999) found that behavioural interventions remain the only treatments with well-documented empirical support for the treatment of feeding disorders including children who are tube dependent. Similar findings were reported eleven years later (Sharp et al., 2010).

Kerwin (1999) reported that effective interventions included contingency management treatments such as positive reinforcement to encourage appropriate eating behaviours, for example social praise or token reward and ignoring or guiding to decrease undesirable behaviours. Only behavioural interventions that met their methodological criteria, namely well-controlled experimental designs were included in the review. Group designs without randomisation were not included. However in recent years there has been an increase in multidisciplinary treatments as research has begun to recognise the contribution of multidisciplinary approaches due to the multifactorial nature of feeding difficulties. Successful transition from tube to oral feeding must include a range of disciplines working together to address the underlying factors that maintain tube dependence (Brown et al., 2013; Wright, 2013a).

Because of the feeding difficulties experienced by tube dependent children, multidisciplinary teams have been developed to assist the child to transition from tube to oral feeding by addressing the underlying factors that cause tube dependency. The most effective interventions in terms of success and time of transition to oral feeding are rapid weaning interventions. These are discussed next as well as the factors that have been found to prevent their effectiveness.

The most effective multidisciplinary approach appears to be rapid weaning in the inpatient/onsite and community settings (Trabi, 2010). This success is generally attributed to the short transition time children make from tube to oral feeding. In rapid weaning hunger provocation is the primary intervention strategy (reducing tube feeds rapidly to induce hunger) (Kindermann et al., 2008). Rapid weaning involves the reduction of tube feeds over the first 5 days of intervention. Programmes reported the majority of children transitioned to oral feeding after approximately three weeks of intervention (Blackman & Nelson, 1985; Brown et al., 2013; Byars, et al., 2003; Cornwell, Kelly & Austin, 2010; Ishizaki, Hironaka, Tatsuni, & Mukai, 2013; Kindermann et al., 2008;

Marinschek, Dunitz-Scheer, Pahsini, Geher, & Scheer, 2014; Trabi, 2010; Wilken, Cremer, Berry, & Bartmann, 2013). Although this type of intervention has traditionally been done in an inpatient hospital environment; in the last few years rapid weaning has been achieved in the outpatient and home care settings (Harding, Faiman & Wright, 2010; Marinschek et al., 2014; Nowark-Cooperman & Quinn-Shea, 2013; Tarbell & Allaire, 2002; Wilken et al., 2013). Inpatient and home based programmes have been most successful in terms of transition time and success rates (Blackman & Nelson; Brown et al; Byars et al; Ishizaki et al., 2013; Kindermann et al; Marinschek et al; Trabi; Wilken et al).

Rapid weaning, despite being the faster method, is not the only method available to transition children to oral feeding. Studies have reported success with gradual weaning interventions, which involves transition over a longer time without using hunger provocation as its main intervention. Studies have reported success (Benoit, Wang & Zlotkin, 2000; Davis, Dean, Mousa et al., 2016; Davis, Bruce, Mangiaracina, Schulz et al, 2009; McKirdy, Sheppard, Osborne & Payne, 2008; Wright, Smith & Morrison, 2011) with gradual weaning techniques in the outpatient and the school setting.

Two case studies of children with neurodevelopmental difficulties who had failed previous rapid weaning interventions were successful in the school and home setting with a gradual weaning protocol (McKirdy, Sheppard, Osborne and Payne, 2008). Children with neurodevelopmental disabilities and older children may take longer to acquire the oral motor skills required to consume an age appropriate diet or to take enough nutrition orally. For children with complex medical aetiologies the transition process needs to progress slowly to allow for oral skill development (Wright, 2013b). Putting these children through a rapid weaning programme when feeding skills need time to develop may result in significant weight loss and difficulty for children regaining it during the maintenance phase. This may lead to the resumption of tube feeding due to risk to growth. Regular monitoring over a longer period appears most beneficial to this group of children (Wright, 2013b; Wright et al., 2011).

Davis et al. (2009) conducted a gradual weaning protocol using analgesia and an appetite stimulant in conjunction with a multidisciplinary outpatient protocol. The nine children in the study had complex medical and developmental difficulties and were given analgesia through post pyloric tube feeds that bypassed the stomach going straight to the small intestine. This was in order to avoid pain and discomfort in the stomach and oesophagus. This treatment was preceded by an appetite stimulant given eight weeks later for a duration of six weeks. Patients were seen for three 1-hour visits during the entire treatment protocol. All participants finished the protocol with no negative side effects, and all transitioned successfully, obtaining 100% of their caloric intake orally.

However, the following factors were found to influence the effectiveness of both slow and rapid weaning in all settings. These are discussed in the proceeding section.

Factors influencing intervention effectiveness for transitioning to oral feeding.

Feeding readiness was found to impact effectiveness of interventions to wean to oral feeding. Participants who were tolerating some foods and fluids prior to intervention did better than those who did not. Davis et al. (2009) reported that prior to the study, intervention to decrease oral sensory difficulties and establish mealtime readiness was done. The authors believed that this prior intervention assisted their pharmacological treatment to help the children transition to oral feeding.

In contrast, Nowark-Cooperman and Quinn-Shea, (2013) reported that a reason for their participants' slower transition time to oral feeding (more than 6 months) was due to minimal intervention addressing the child's feeding reluctance prior to their programme. Wright (2013b) believed that children should be prepared for future transitioning with appropriate input from SLTs and dietitians to address oral sensitivity through regular messy play and oral stimulation, in order to increase the likelihood of their success. Therefore, it seems important to consider feeding readiness prior to tube removal especially if preparing for a rapid weaning programme.

The age of intervention for tube weaning may affect transition success (Ishizaki et al., 2013; Marinshek et al., 2014; Wright et al., 2011). Ishizaki et al. (2013) found that children referred for tube weaning from the age of three or over had a markedly longer treatment time, compared to children under this age. Marinshek and colleagues suggested that age might be a factor in transition time as their rapid weaning via internet coaching was quicker than an inpatient approach. However, this was most likely due to a majority of younger children in their home cohort compared to the inpatient cohort. Wright et al. (2011) found that slow or failed weaning often occurred for children five years and over. Findings suggest that the age at which children are weaned from tube feeding might be a significant factor that may contribute to tube feeding dependence. The largest cohort of tube dependent children in New Zealand is over five years of age (Jelleyman, 2013).

Wright (2013a) suggested that another reason for difficulty transitioning children from tube to oral feeding might be simply due to the lack of assistance by professionals. She reported that many parents sought help overseas because they were not being assisted in the United Kingdom from health professionals even though the principles of tube withdrawal/weaning were relatively straightforward.

Jelleyman (2013) found that SLTs were commonly identified as an important to tube withdrawal/weaning, and in a few places workforce shortages of SLTs were noted as a limitation to developing this work. Dunitz-Scheer et al. (2011) believed that thousands of survivors of modern

neonatal medicine are literally prevented from learning to eat because of lack of information, lack of diagnostic definition, and the lack of clear guidelines and clinical expertise.

Research Question

Based on the findings discussed in the literature review this proposed study addressed the key issues in the context of tube feeding dependency in children in New Zealand. This study gathered data across a range of services (health setting vs. education setting) in New Zealand and locations (urban vs. rural). There has been research done on multidisciplinary interventions to help transition from tube to oral feeding in tube dependent children, as well as factors that appear to be preventing that transition. What has not been examined is the speech language therapists' perspective into why tube feeding dependency is occurring and what is affecting transition to oral feeding in New Zealand.

The importance of the SLT perspective in New Zealand is that paediatricians in New Zealand have identified the speech therapist as a key professional to work with tube fed children (Jelleyman, 2013). The research question for the study is "What are the factors contributing to tube feeding dependency in children from the SLT perspective?"

Chapter 3- Methodology

This chapter outlines the methodological approaches underpinning this study. The mixed methods research design is outlined with the rationale for this approach. The explanation of the data collection methods and the analysis framework is then described. It concludes with a summary of the ethical considerations of the study.

Study Design: Sequential explanatory approach

The research design used for this study was a mixed methods sequential explanatory design (Creswell & Plano Clark, 2011; Giddings & Grant, 2006). This study began with the collection and analysis of quantitative data, via a survey. This was the priority for addressing the study's question; "What factors contribute to paediatric tube feeding dependency in New Zealand as perceived by SLTs?" This survey was then followed by semi-structured interviews for the qualitative data.

This design was chosen, as the aim of the study was to assess trends and relationships with quantitative data but also to be able to explain the mechanisms or reasons behind the resultant trends for tube dependency in children from the SLT perspective (Creswell and Plano Clark, 2011). However, due to the Massey University Human Ethics Committee (Northern) wanting to view and approve interview questions before the survey analysis, the study consequently did not follow the sequential explanatory design doctrine outlined by Creswell & Plano Clark. This will be further explained later in the chapter.

What is mixed methods research?

Mixed method research is the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, concepts or language into a single study (Johnson & Onwuegbuzie, 2004). Gaining an understanding of the strengths and weaknesses of quantitative and qualitative research puts a researcher in a position to mix or combine strategies. According to this principle, researchers should collect multiple data using different strategies, approaches, or combinations of strategies, as this is likely to result in complementary strengths and non-overlapping weaknesses of the methods (Johnson & Onwuegbuzie, 2004).

Worldview

The author proposed that two paradigms or worldviews in this study changed and shifted from post positivism to constructivism as the author used two philosophical assumptions throughout the study. In this study a quantitative method (survey) was used at the beginning of the study,

which assumed that the researcher was using a post positivist worldview to inform the study, beginning with specific variables, empirical measures and often framed within an a priori theory that is being tested in the survey project (Creswell and Plano Clark, 2011). Post positivism, makes claims for knowledge based on (1) determinism or cause and effect thinking; 2) Reductionism, by narrowing and focusing on select variables; and (3) the testing of theories that are continually refined (Creswell & Plano Clarke, 2011; Silfie & Williams, 1995). Grant and Giddings (2002) reported that historically the post positivist shift in thinking has enabled the integration of quantitative and qualitative methods so that a problem could be investigated incorporating the subject's experiences of the phenomenon. So with this study, following the survey the worldview shifts as the study moved to the qualitative phase to follow up and explain the survey results. This shift was to a constructivist perspective.

Constructivism examines understanding or meaning of phenomena, formed through participants' subjective views. In this form of enquiry, research is shaped from individual perspectives to broad patterns and ultimately to broad understandings. In the semi-structured interviews, the attempt was to elicit multiple responses from the participants, to build a deeper understanding than the survey would produce, and to generate a pattern of responses that explained the survey results (Creswell and Plano Clark). Figure 1 shows the sequential explanatory approach for this study. This figure shows the mixed method approach that began with the collection and analysis of numeric data then an inductive approach to further explain and add depth to the data. For the study to achieve ethical approval the ethics board requested that they see and approve the interview questions before the survey was analysed. The results of both phases were then integrated for the purpose of explanation in the discussion chapter.

Participants:

Participant recruitment

Participants were recruited through a professional email network in New Zealand: The National Child Dysphagia Special Interest Group. Inclusionary criteria for the participants were: i) They were practising SLTs in New Zealand and (ii) They had worked with children who were tube fed in the last five years. Permission was sought from the convenor of the special interest group (SIG) to email the information sheet (Appendix A) to the members of the SIG. At the end of the information sheet was a link to the online survey.

Forty-eight participants participated in the survey but only forty-three responses were analysed. Twenty-six participants from the survey indicated that they were willing to participate in an interview, from which ten were randomly selected. All participants were interviewed face-to-

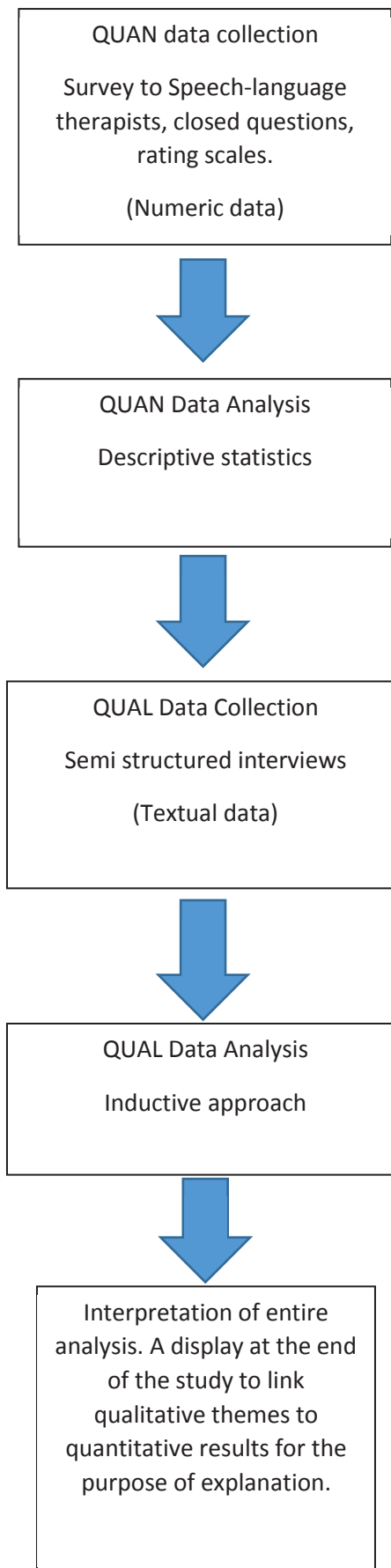
face, three in their homes and the rest at their workplaces. To protect confidentiality, the names of the participants and their places of work were not recorded. Questions asked were semi structured open-ended questions, (see Appendix D). Interview questions were formulated for the ethics application, as requested by the ethics committee, rather than after analysis of the quantitative survey and their findings.

Survey

An online survey was used in the initial stage of the study. The survey was designed using Survey Monkey® for the SLTs working with tube fed children in the health, education, and private sectors across New Zealand. Online surveys present a time and cost efficient method of data collection. Surveys have the benefit of allowing respondents to complete the survey at any time that is convenient for them, and significantly reduce the data input time required prior to the analysis phase (Dillman, 2007; Wright, 2014). Surveys also focus on obtaining information about activities, beliefs, preferences and attitudes by direct questioning (Irwin, Pannbaker & Lass, 2013).

Forty-two questions were developed and the survey organised into five sections. Section One (questions 1-2) ensured inclusionary criteria was met, using two close-ended questions. Section Two (questions 3-7) was designed to obtain demographic information about the participants. For example, the background of speech-language therapists including: age, years of experience with tube dependent children, gender, ethnicity, workplace, and location of workplace (rural or urban). This demographic data was obtained to determine if there were any relationships between these variables and the survey responses (Punch, 2003). Section Three (questions 8-14) contained seven closed questions regarding SLT caseload information and current practices. This section included general caseload numbers, the number of tube fed children on their caseloads, and the types of tubes these children had. This was to gather information about activities and preferences in practice. Section Four investigated the management of tube fed children (Questions 15, 16, 17, 39, 40, 41, 42 and 43). These questions were a mixture of close-ended and statements using Likert scales (Likert, 1932). The statements and questions were designed to obtain the SLTs' perceptions about professional knowledge and management strategies for tube weaning. The final section (questions 18- 38) measured the SLTs' agreement about factors contributing to tube feeding dependency from the literature; from strongly agree to strongly disagree (see Appendix G).

Figure 1: Sequential Explanatory Design (adapted from Creswell & Plano Clark, 2011, pg. 64)



Pilot Survey

A draft copy of the survey was sent to an expert in paediatric tube feeding. The expert was asked to review and give feedback about the survey content in relation to the research questions. This draft survey was then given to two independent SLTs who were asked to complete the survey and provide feedback about their overall impression of the survey. They were also asked to comment on the relevance and comprehensibility of the questions. This feedback was incorporated into the final survey and included rewording of three questions to help improve clarity.

Data Analysis

Descriptive statistics was used to analyse the results of the online survey. Percentages and ranges (difference between the highest and lowest score) were computed for the demographic information, while modes were used for the frequency data to look at potential patterns (Irwin et al., 2013). Likert-type or frequency scales used fixed choice response formats and are designed to measure attitudes or opinions (Burns & Grove, 2005; Punch, 2003). See Appendix D for the survey questions. Modes, frequency counts, and ranges were obtained for these responses in order to gather what occurs most frequently in the targeted population to see relationships to opinions and attitudes (Irwin et al., 2013).

Semi-structured interviews

Interview participants

At the conclusion of the online survey, permission was sought to contact consenting participants for individual semi-structured interviews. A link allowed these participants from the survey to view the information sheet regarding the second study phase (Appendix B). They could then leave contact details for the author to take part in the second qualitative phase if they wished.

Interview questions

Semi-structured interviews allow the interviewer to gather data in a conversational format using a set of predetermined, open-ended, and specific questions (Irwin et al., 2013). The benefit of this style of interview is that it can produce rich and valuable data with the aim of the interviewer to encourage a prolonged and intimate conversation (Punch, 2005).

Data analysis

The recordings of the interviews were transcribed (Appendix F). The data was then analysed by a general inductive approach as described by Thomas (2006). This inductive approach was selected to analyse the data and interpret meaningful themes. The approach does not impose theoretical models on the data. The general inductive approach uses detailed interactive readings of the raw data to derive initial categories or codes. The author and her qualitative supervisor initially undertook the process independently, followed by crosschecking for consistency. Links and relationships between categories were established, from which a framework of key themes were developed. The data was prepared and analysed using the five steps as described by Thomas. Thomas uses the terms category/theme interchangeably but appears to use the word, category primarily. These steps are further described below:

- 1) Raw data files prepared (data cleaning):** Each interview was formatted into files of common format. Each interview was typed using italic font for the interviewer's questions and non-italic font for the participants' responses by the professional transcriber.
- 2) Close reading of text:** Once the text was prepared, the raw data text was read in detail until the author was familiar with its content and an understanding was gained of the themes and events covered in the text.
- 3) Creation of categories:** Categories and sub categories were identified and defined. Categories were created from actual phrases in specific text segments. These marked text segments were then copied into a document of emerging categories. The author did this by colour coding each category and then allocated phrases and text segments into each category.
- 4) Overlapping coding and uncoded text:** Some segments of text were coded into more than one category as final themes were developing. A considerable amount of the text was not assigned to any category, because much of the data collected extended beyond the study's question. This situation was inevitable as responses to the research question intersected with multiple areas of the SLTs' work and concerns.
- 5) Continuing revision and refinement of category system:** Once the categories were defined sub topics were searched for including contradictory points of view and new insights. Appropriate quotations were selected that conveyed the core theme or essence of the category. Thomas (2006) reported that the intended outcome of this process is to create a small number of summary categories (between three and eight). These summary categories represent the key aspects of the themes identified in the raw data and were assessed to be the most important themes given the

researcher's objectives (Thomas, 2006). Four themes were identified from the raw data with between three to eight summary categories found within those themes, see Chapter 5.

Limitations of Study

For the qualitative phase of the study, the participants selected were those who volunteered to be interviewed. Their survey answers were unknown to the researcher. Due to the small population of speech-language therapists working in the field of paediatric feeding disorders and tube feeding dependency in New Zealand it was a priority to ensure anonymity. Creswell and Plano Clark (2011) believe that in studies where identifying information cannot be collected as part of the qualitative data this approach is necessary. Creswell and Plano Clark report that this selection approach may provide a weaker connection between the qualitative and quantitative phases rather than using a systematic approach. A systematic approach uses the quantitative results to follow up sampling procedures to select participants best able to explain the survey results. That is linking the two phases by following particular participants from the survey into the interviews (Creswell & Plano Clark, 2011).

There were some methodological issues with the research. The author was unable to follow the sequential explanatory design principle regarding developing the interview questions after the analysis of the survey results. That is, the survey data needed to be analysed prior to the development of the research interview questions; then a subsequent ethical approval was required for these questions. This was due to the Northern Massey University Ethics Committee wanting to view and agree to the interview questions before ethical approval could be granted. Creswell and Plano Clarke (2011) report that it can be difficult to secure ethics approval for sequential explanatory designs because the researcher cannot specify how participants will be selected for the second phase until the initial findings are obtained. The study has because the interview questions were not developed after the survey analysis; therefore, the results may be limited as the author was not able to link interview questions directly to the survey results.

Another possible limitation to the study is the occurrence of research bias. The researcher's own beliefs or assumptions can influence how the interviewees act and respond in an interview situation as well as affect the interpretation of the data (Patton, 2002). A social desirability bias may have also occurred (Coolican, 2004). The interview participants may have answered what they thought sounded better rather than what had actually occurred at their workplace with tube dependent children. In addition, the participants may have been more aware and interested in tube dependency and therefore more likely to respond to the survey. Therefore, the results may not be truly representative of the perspectives of the SLTs across New Zealand involved with tube fed children.

Ethical Considerations

A human ethics application was submitted and approved by the Northern Massey University Ethics committee (MUHEC), MUHECN: 001/15 (see Appendix F). All participants were informed through email about the reasons for the study and that participation was voluntary. Written consent to participate in the qualitative part of the study was obtained from those who volunteered. Participants were advised that they could withdraw from the study at any time (see Appendix C). Raw data including completed survey data and transcripts have been stored securely in a locked cabinet only accessed by the author and her supervisors. These will remain stored for a period of five years as required by the ethics committee. Once the survey period was complete, the survey was closed on Survey Monkey®.

Participation in the interviews involved a time commitment from the participants. Participants were compensated for their time with a \$25 voucher as approved by MUHEC. Information about compensation was outlined at the end of the information sheet for interview participants (see Appendix B).

Summary

This chapter has introduced the methodology and methods for data collection and the analysis used for this study. The sequential explanatory design consisted of a quantitative phase (survey) and a qualitative phase (semi-structured interviews). Ethical considerations were outlined and decisions by the MUHEC were described. The results and findings of this investigation are presented in the next two chapters. The results begin with the results of the survey in chapter four and interviews in chapter five. These results come together in Chapter Six as the primary findings of this research project are discussed.

Chapter 4- Quantitative Results

Quantitative data was collected using an online survey. The number of participants included in the data analysis is reported below, followed by the results from the components of the online survey: demographic information, caseload information, and responses to the statements on the Likert scales.

Data cleaning

Forty-eight participants participated in the survey. However, only forty-three responses were analysed. The reasons for discarding the five survey responses included: One SLT did not currently work as an SLT in New Zealand and four others did not complete the second part of the survey. They did not respond to the Likert Scale statements and omitted some of the demographic questions. The demographic data from these five SLTs were discarded to ensure that the results were an accurate reflection of those who participated in the entire survey. Forty-three surveys were analysed in total.

Demographic Questions

Table 1 displays the demographic data for the forty-three SLT participants who completed the online survey. The majority were experienced clinicians, working full time for the New Zealand health service in an urban setting.

The age of the children they worked with ranged from new-borns to children over 15 years, with the majority of participants working with children from 1-3 years of age (79%). All but three participants (93%) currently had tube fed children on their caseload. The remaining three had had experience with tube fed children in the last 5 years (See Table 1).

Participant caseload variables

Table 2 displays the caseload information of the SLT participants. Most participants (25%) responded that on average they had approximately 21-30 children on their caseloads. More than half of the participants responded that they had five or more tube fed children on their caseload. Most of the children on their caseloads had PEG tubes (n=157) followed by NGTs (148).

The main professionals identified as working with SLTs to manage tube fed children were paediatricians and dietitians (97.67%) followed by nurses (81%) and SLTs from other services (67%). Table 2 shows that the most frequent professional development or learning about tube feeding was

Table 1: Demographic data of SLTs working with tube fed children

Years of experience % (n)	Employment contract % (n)	Geographical setting % (n)	Employment setting % (n)	Age of general caseload % (n)
10-20 = 25.58% (11) 3-5 years= 23.25% (10) 20+ = 20.93% (9) 6-10 = 16.28% (7) 1-2=13.95 (6)	Full time=72.09% (31) Part time=23.26% (10) Self-employed= 2.33% (1) Not currently employed, e.g. parental leave=2.33% (1)	Urban= 58.14% (25) Mixed = 34.88% (15) Rural= 6.98% (3)	DHB=67.44% (29) Special School=20.93% (9) Non-government organisations=6.98% (3) Private Practice=6.98% (3) Ministry of Education=2.33% (1)	1-3yrs=79.07% (34) 0-1yrs = 72.09% (31) 3-5yrs = 65.12% (28) 5-14yrs = 69.77% (30) 15+ = 44.11% (19)

Table 2: Caseload information of SLTs working with tube fed children

Tube fed children currently on caseload % (n)	Tube fed children on caseload % (n)	General caseload volume % (n)	Have you managed tube fed kids in last 5 years % (n)	Children fed via the types of tube feeding. (n)	Identify other professionals who you work with or have worked with in the past to manage tube fed children. % (n)	What kind of learning/development have you had in tube feeding? % (n)
Yes = 93.02% (40) No = 6.98% (3)	5+ = 58.14% (25) 3 = 13.95 (6) 4 = 9.30% (4) 2 = 6.98% (3) 0 = 6.98% (3) 1 = 4.65% (2)	21-30 = 25% (10) 50+ = 20% (8) 31-40 = 20% (8) 11-20 = 12.5% (5) 1-10 = 12.5% (5) 41-50 = 10% (4) 3 skipped this question	Yes = 100% (14) 29 skipped	Gastrostomy (button & peg) = 157 Nasogastric tube (NGT) = 148 Gastrojejunostomy tube (GJT) = 7 Nasojejunal tube (NJT) = 3 Nasodeudanal tube (NDT) = 1 Orogastric tube (OT) = 1	Paediatrician = 97.67% (42) Dietitian = 97.67% (42) Nurse = 81.40% (35) SLT from other provider = 67.44% (29) Psychologist = 58.14% (25) Occupational Therapist = 58.14% (25) Visiting Neurodevelopmental therapist = 55.81% (24) Teacher = 46.51% (20) Teacher Aid = 41.86% (18) Other medical specialist = 41.86% (18) Lactation Consultant = 39.53% (17) Social Worker = 39.53% (17) Physiotherapist = 37.21% (16) Early Intervention Teacher = 23.26% (10) Education Support Worker = 20.93% (9) Specialist teacher = 11.63% (5) Other (not specified) = 9.30% (4) SENCO = 2.33% (1)	Assistance from professionals = 86.05% (37) Professional materials = 76.74% (32) Self-directed learning = 74.42% (32) Conferences/Seminars = 67.44 (32) Supervision = 62.79% (27) In-service = 55.81% (24)

Table 3: Management information of tube fed children (Questions 15, 16, 17, 39, 40, 41, 42 and 43)

15. How significant is the management of a child's tube feeding in relation to your overall management of that child?	Moderately significant Very significant Significant Of little significance Not significant	14 17 12
16. How frequently do you address tube feeding issues with your client and the client's family?	Very Frequently Frequently Occasionally Rarely Never	8 22 10 3
17. How prepared do you feel to address tube feeding issues in the context of your speech-language therapy sessions?	Very prepared Prepared OK Not prepared Not at all prepared	6 20 15 2
39. I require additional training, to adequately manage transitioning infants and children from tube to oral feeding.	Strongly Agree Agree Undecided Disagree Strongly Disagree	9 30 2 2
40. Additional team training is needed to help transition children from tube to oral feeding.	Strongly agree Agree Undecided Disagree Strongly disagree	9 28
41. At what level should this training be provided?	University-undergraduate University-post grad level Short courses Conferences/seminars Assistance from other professionals Self-directed learning Online learning Other	21 23 41 34 29 25 25 3
42. What strategies have you and your team members used to encourage oral feeding whilst tube feeding.	Reducing the volume of tube feeds Alternating tube and oral feeding Overnight tube feeds (night) Messy food play Encouraging sucking during feeding SOS/ feeding interventions Mouthing toys	37 23 33 40 36 36 37

through discussions with other professionals (86%) followed by professional books and journals and self-directed learning.

Management of tube fed children

Table 3 shows the results of the seven questions related to the management of tube fed children by the SLTs. Most participants (mode = 17) reported that tube feeding was very significant in terms of the overall management of the child. Responses ranged from significant to very significant. Many participants felt prepared (mode = 20) to address tube feeding issues. Responses for this question ranged from not prepared to very prepared. The SLTs also indicated that this occurs frequently in their practice (mode =22), responses ranged from rarely to very frequently.

Although a large number of participants (mode =20) felt prepared to address tube feeding issues they felt that they required additional training (mode =30). The range for this question was from strongly disagree to strongly agree. The majority of participants also indicated that training was also required for the multidisciplinary team (mode =28). This question's responses ranged from agree to, strongly agree. There majority of SLTs responded that short courses were an appropriate medium for this training (mode =41).

The type of treatment strategies used the most by SLTs to encourage oral feeding was messy food play (mode =40). This was followed closely by reducing tube feeding volumes (mode =37) and encouraging mouthing and play with non-food items (mode =36). This questions asked participants to select as many options as possible.

Responses to perspectives about tube feeding dependency

The final twenty questions (18-38) reported in Table 4 asked about specific factors related to tube feeding dependency in children. Table 4 shows that SLTs had either clear agreement or disagreement with the statements with only one question showing that the majority were undecided and another that had an equal split between agree and disagree.

Table 4 shows that most participants agreed that there were eight factors that contributed to tube feeding dependency. These factors were; children not taking enough oral intake at mealtimes (mode =33) , responses ranged from strongly agree to strongly disagree; children's negative reaction to oral feeding (mode = 32), this ranged from strongly agree to strongly disagree, and fatigue issues during oral feeding (mode =24), the responses ranged from agree to strongly disagree. Insufficient clinical time to transition from tube to oral feeding (mode = 23), responses ranged from strongly agree to disagree; parental concerns about their child's nutrition (mode =22), the range was from agree to strongly disagree; medical issues (mode =20), the range was from

strongly agree to strongly disagree; gastroesophageal reflux (mode =20). These responses ranged from strongly agree to strongly disagree and vomiting (mode =17), this ranged from strongly agree to strongly disagree. Table 4 shows a high response rate of undecided responses for these factors, (see Table 4 questions 25-27).

Most participants agreed that transitioning children from tube to oral feeding was a priority (mode =22), responses ranged from strongly agree to disagree. Similarly SLTs felt their MDT prioritised transitioning children from tube to oral feeding (mode =22), the responses ranged from strongly agree to strongly disagree. SLTs reported feeling confident about addressing tube feeding and to advocate for it in their workplace (mode =21), the responses ranged from strongly agree to disagree. The majority of SLTs agreed that they felt experienced with tube feeding (mode =21). Their responses ranged from strongly agree to disagree.

Table 4: Frequency counts of attitudinal responses of participants to tube feeding dependency

	Statement	Response*						Mode
		SA	A	U	D	SD		
18.	I am experienced working with tube fed children.	8	19	9	6	1	A	
19.	Children are tube dependent due to their medical condition.	5	20	8	9	1	A	
20.	Children are tube dependent due to parental reluctance to transition them to oral feeding.	0	14	6	20	3	D	
21.	Children are tube dependent because of team reluctance to reduce tube feeds.	4	12	8	18	1	D	
22.	Children are tube dependent due to the child's negative reaction to oral feeding.	5	32	2	3	1	A	
23.	Children are tube dependent due to insufficient clinical time to address transitioning from tube to oral feeding.	8	23	8	4	0	A	
24.	Children are tube dependent due to lack of confidence of the team to attempt transitioning from tube to oral feeding.	3	15	9	15	1		
25.	Children are tube dependent due to having issues with gastro-oesophageal reflux.	2	20	13	7	1	A	
26.	Children are tube dependent due to having regular vomiting episodes.	4	17	11	9	2	A	
27.	Children are tube dependent due to parental concerns about their child's nutrition.	0	22	11	9	1	A	
28.	Children are tube dependent because they are now too old to transition to oral feeding, e.g. they are now school aged.	0	1	11	25	6	D	
29.	Children are tube dependent because they are too young to transition to oral feeding, e.g. they are under 12 months of age.	0	6	5	25	7	D	
30.	Children on my caseload are tube dependent due to fatigue issues during oral feeding.	0	24	6	10	3	A	
31.	Children are tube dependent because they do not take enough orally at mealtimes.	5	33	3	2	0	A	
32.	Transitioning tube dependent infants and children from tube to oral feeding is a high priority.	14	22	4	3	0	A	
33.	I am confident to advocate transition from tube to oral feeding for my clients in my workplace.	8	21	7	7	0	A	
34.	The team I work with see transitioning children from tube to oral feeding as a high priority	5	22	9	5	2	A	
35.	Parents/caregivers of tube dependent children are reliant on the feeding tube and reluctant to end tube feeding.	1	8	12	19	3	D	
36.	Parents/caregivers of tube dependent children are motivated for tube withdrawal.	9	24	9	0	1	A	
37.	It is easier to transition children from tube to oral feeding when they are under 1 year	3	14	22	4	0	U	

	of age.												
38.	Tube dependent children, who are 5 years and over are able to transition from tube to oral feeding.	4	26	12	1	0							A
Note. *SA=Strong Agree, MA=Moderate Agree, U=Undecided, MD=Moderately Disagree, SD=Strongly Disagree.													

Table 4 shows that parental reluctance to transition their child to oral feeding was not a major factor (mode =19), the range of responses were from agree to strongly disagree. The SLTs also disagreed that children were too old to be transitioned from tube to oral feeding when they were school age (mode =25), responses ranged from agree to strongly disagree. In addition the SLTs disagreed that children under 12 months of age were too young to transition to oral feeding (mode =25), their responses ranged from agree to strongly disagreed. Yet the SLTs were undecided if it was easier to transition children under 12 months (mode =22), their responses ranged from strongly agree to disagree (see Table 4).

The participants appeared undecided if the MDT lacked confidence in transitioning children from being tube fed to oral feeding. An equal number of participants agreed (15) and disagreed (15), responses ranged from strongly agree to strongly disagree (see Table 4).

Summary

The results of the survey showed that most of the SLTs who participated in this study were experienced clinicians. They worked full time for the Ministry of Health in an urban setting. Forty participants currently had tube fed children on their caseload with the remaining three having worked with this population within the last five years. At the time of the survey, the majority of the SLTs worked with pre-school aged children (1-3 years). Most SLTs had a caseload of approximately 20-31 children, in which over five children on their caseload were tube fed.

There was clear agreement that eight factors contributed to tube feeding dependency. They were children's medical condition, negative reaction to oral feeding, parental concerns, reflux, vomiting, and fatigue during oral feeding, insufficient oral intake, and insufficient clinical time to transition children to oral feeding. Participants disagreed that parental reluctance to transition to oral feeding and the age of the child at transition were factors related to tube feeding dependency.

Chapter 5- Qualitative Results

Results from the semi-structured interviews are reported in this chapter. Ten participants were interviewed and the results were coded into four themes and subsequent sub categories. As part of a sequential explanatory design, the overall purpose was to use the data from the semi-structured interviews to explain the initial quantitative results (Creswell & Plano Clark, 2011).

Results from the semi-structured interviews

Twenty-six participants indicated that they would be interested in participating in the interviews. Of these twenty-six participants, ten were chosen at random to be interviewed.

Table 5 shows that participants were experienced female speech and language therapists who had worked for over five years. The majority of participants were employed by the Ministry of Health and worked full time. Half of the participants worked across urban and rural locations whereas the other half worked only in urban locations.

Table 5: Interview participants' information

Participant	Years of experience as an SLT	Male /female	Location	Work setting	Employment contract
1	23	F	Urban	Education	Part time
2	7	F	Urban	Education	Full time
3	35	F	Urban/rural	Health	Full time
4	10	F	Urban	Health	Full time
5	10	F	Urban	Health	Full time
6	17	F	Urban/rural	Health	Part time
7	8	F	Urban	Health	Full time
8	10	F	Urban/rural	Health	Full time
9	35	F	Urban/rural	Education	Full time
10	40	F	Urban/rural	Health	Part time

The interview settings for the participants varied. Two participants were interviewed in their homes. The other eight interviews were conducted at their place of work. All interviews were audio recorded and transcribed using the process of intelligent verbatim. This is a process that eliminates hesitations, pauses and repetitions and overlapping talk between interviewer and participant, to aid clarity of reading, while ensuring that the transcription remains faithful to the participants' meaning (Irwin et al., 2012; Punch, 2005; Creswell & Plano Clark, 2011).

Qualitative Validity

Member checking

Member checking is used frequently in qualitative research as a measure of reliability to ensure that the results are an accurate reflection of the participants' experiences (Creswell & Plano Clark, 2011). Once the interviews were transcribed, participants were given the opportunity to revise and amend their transcripts (see Appendix C). Two participants asked to review their transcripts (participants 3 and 9). These transcripts were sent to the participants to check for accuracy. Participant 3 corrected the spelling of an overseas tube weaning programme as well as the names of an overseas SLT and psychologist who she had been in contact with regarding tube weaning. Participant 9 brought attention to a word change and removed some specific information; a regional town was mentioned by name as well as the name of the hospital she had worked previously. She also made three spelling corrections.

Interview themes

After the data had been coded as described in Chapter 3 four themes were derived from the data. Through a general inductive approach to analyse the qualitative data, these themes and related subthemes were developed (Thomas, 2006). The themes are described below. The first theme was: *parents are integral to outcomes*. This theme contained eight sub-themes: tube feeding interfering with bonding and maternal identity; parental and child stress at mealtimes; reluctance to stop tube feeding due to weight loss concerns; parental dependence on tube feeding; the need for psychological input; parents seeking intensive support; barriers to family mealtime culture and cultural differences; Pacific culture. The second theme was *developmental and structural obstacles for school-aged children*. The sub-themes were: Normalisation of tube feeding by school age; the increase in medically fragile non-funded children for child development caseloads and the change of service delivery as the child gets older. The third theme was *service delivery issues*, which contained five sub-themes. They were; the impact of philosophical differences between health and education services in New Zealand, confidence of education support staff skills to support oral feeding; challenges for the SLT to advocate for tube dependent children, lack of joint planning and communication across the MDT for the tube fed child and planning for transition to oral feeding in the future. The fourth theme identified was *tube feeding and negative sequelae*, comprising of four sub-themes; lack of appetite; scheduled feeds reducing appetite development in premature infants; aversive sequelae; pain. Presented in the next section are the four themes and their sub-themes, demonstrating the web of inter-related complexities that contribute to tube feeding dependency.

Parents are integral to outcomes

During the interviews, participants reported a range of issues associated with parental attitude and anxiety about tube weaning. These issues included grief associated with tube feeding, parental stress when encouraging oral feeding and parental concerns about weight loss for their child and subsequent reliance on the tube. Other sub-themes found included the loss of family mealtimes and cultural differences that affected parental attitude and anxiety.

Tube feeding interfering with bonding and maternal identity

The majority of interviewees reported that tube feeding in infancy appears to affect the mother child bonding. They also perceived that tube feeding interfered with a mother's confidence in feeding and providing for her child. Two participants spoke about the effect on mothers not being able to feed their child orally and their feelings of failure:

..It's huge for families. And then I think there's also guilt for the mothers and not being able to provide for your child. You know...it's such an innate thing in every culture to feed your child. And when that's disrupted I think there's huge ego you know, self-esteem and ego issues for the parents. (p7)

It's definitely such a stressful situation, for all parents to have a tube fed child and you know, I think especially for the mothers... because feeding, feeding a baby is sort of one of the main roles and if they're not able to feed their baby then that can be really, really difficult for them. And they feel often that they're missing out on that bonding time around feeding and if feeding's a stressful negative experience then that can be really upsetting. (p4)

Interviewees thought that parent-child bonding was negatively affected between the mother and infant when a child was tube fed in early infancy. The comments from one participant draws attention to the effect that this disruption of bonding has on future parent-child interactions, highlighting the stress that mothers face when they have a tube fed child:

Those who leave NICU [neonatal intensive care unit] being tube fed there are attachment issues between mum and baby and bonding issues. And they are the parents we all try to get to mother craft when we do take tubes out and try to get the sleep and feeding and everything happening. And, the mums turn into baby's nurse and then they don't get to be mum and then later on they seem to really struggle to get down on the floor with their child and do the fun stuff. (p8)

This comment shows how the mother appears to have a medical rather than a parental role. She has turned into a carer and nurse rather than a mother. This change in her role has most likely affected the future relationship between her and her child.

Parental and child stress at mealtimes

Participants reported tube feeding caused negative parent child interactions at mealtimes. These begin in infancy and continue for families, as the child gets older. This participant recounts the mealtime stress she witnessed at a recent home visit:

They're stressed. Really stressed. And I could tell, as soon as it started, they build up to the feed, getting the bottle ready you know. Everyone was starting to get on edge and get stressed. It's really hard. (p5)

The impact of the daily stress around feeding creates a cycle of anxiety around mealtimes and oral feeding for families, which the next participant described:

Often they talk about, the tube feeding being the most stressful part of the child's issues. And you know they can be very anxious and that can lead to a cycle of anxiety around mealtimes, mealtimes not being a very positive experience. In some cases you know, sort of force feeding the child and then feeding becomes a negative experience and can lead to oral aversion and anxiety for the child around mealtimes. So, I think that's definitely, a big impact. Some of the families that are a bit more relaxed around feeding, the children seem to do better. (p4)

A more relaxed parental attitude at mealtimes appeared to lead to better feeding outcomes for these children. Force feeding and other negative experiences around tube feeding may result from heightened parental stress at mealtimes.

Reluctance to stop tube feeding, due to weight loss concerns

The majority of participants commented that transitioning the child from being tube fed to orally feeding is difficult because of parental concerns about their child losing weight.

Because the constant weighing I think, is also a very stressful factor for parents. And I wonder sometimes whether it's necessary....She was happy that he was gaining weight. For some families just a child losing a few ounces of weight is hugely stressful. (p3)

The constant weighing of the tube fed child has created another anxiety cycle for parents not only about mealtimes but also about weight loss. For many of the families of tube fed children reliance

on tube feeding and measuring calories and weight started in infancy. This medical role of weighing and counting calories is hard for parents to let go:

I've definitely had families that, it's really hard to get rid of the tube even when the child's doing quite well it's really hard...for them to step away from it because they always have that backup.., well if the milk (oral feeding) doesn't go well then we know they've got the calories. Or, yes I've had a really good breast feed but I'm just going to give him a bit of a top-up anyway, you know. It's very hard to get them to step away from that support...It's the parachute of always having, to be able to give a tube feed if needed. And I think when parents have that initial stress and anxiety of, especially a neonatal experience and becoming so focused on weight gains that they lose sight of typical children and normal development and normal weight fluctuations. (p7)

This participant reflected on her experiences with families where tube feeding was normalised and relied on even if their child was developing well. A consequence of the parents' experiences in infancy and the medicalisation of the parental role has led to this reliance on the tube even when their child has the ability to be an oral feeder.

Parental dependence on tube feeding

Participants commented that some mothers would actively ignore and deliberately give misleading information to health professionals to prevent the reduction of the tube feed and eventual withdrawal of their child's feeding tube:

He was looking like he was doing really well, he was really enjoying it. But she was still putting expressed milk down his tube at the end of the day. Like he was getting really heavy, he was putting on too much weight. And she was told, right next week I'm going to reduce the amount, with the idea of getting the tube out. So I'd go back a few weeks later and it was still in, she was putting the same amount in. She would tell me different amounts from the community nurse. And she would tell us both very different stories. And it worked out that the mum just didn't want to get rid of the tube. (p6)

Participants expressed insights into the challenges of working alongside parents, endeavouring to maintain a professional relationship, often in instances where the clinical knowledge shared by the SLT was rejected by the parents. This next participant reported that the reason why a parent was unable to reduce the volume of milk she was giving to her child was due to past issues:

So the paediatrician felt that the main reason he wasn't eating was because he was having all this milk. And you know, we worked with mum but she just found it really, really

difficult. She wasn't able to cut down his milk. And she'd had quite a lot of trauma in her past and just yeah, had real difficulty. I think there was a lot of about the little boy growing up and she wanted to keep him as a baby. (p4)

Participants indicated that they had compassion and understanding of the mothers' reluctance to wean their children. They also reported that expert medical opinion alone was not necessarily enough to shift parental concerns. Specialised input from a mental health professional is required in these situations because the psychological issues associated with tube weaning are beyond the scope of an SLT. One participant discussed the reluctance of parents to engage in feeding programmes to reduce tube feeds because of the marked change it would cause to the family routine. This lack of engagement also relates to the parents' reliance on the tube to feed their child:

I think some families find it difficult to understand why we want to get kids off tubes when we have put them in. It varies so much for so many different people, like some of them absolutely hate the thought of having a tube but it can be a great stress reliever and when we start talking about taking that away suddenly they have that job of feeding and the therapy for the feeding skills and it is a big burden sometimes. And then often all the behavioural stuff that goes with that change, I think that can be quite a hurdle for families to want to engage in feeding programmes. (p8)

This parental reluctance to give up the feeding tube even when their child no longer required it for nutrition is beyond the scope of SLTs in terms of their clinical expertise, requiring specialised support. Support from psychologists around parental concerns about tube dependence was another theme that was discussed by the participants.

The need for psychological input

The above comments highlighted the SLTs' awareness of the complex family dynamics and contextual issues that affected their ability to work effectively with children who are tube fed. Some participants identified a lack of psychological support for families as a gap in service provision. They felt that this lack of psychological support affected the management of the child. The SLTs interviewed recognised that some parents found tube removal difficult to accept because it was critical for their child's survival in the past:

..It becomes a crutch. And I think there's a lot of work that should be acknowledged that needs to be done with families. And the reason that the child's on a tube is because he was failing at something. You take away that tube but then you might have to put it down again. You know, there's so much. I often think that there should be a psychologist on the

team or we should have some training on how to handle that information and how to handle, 'right we're not going to change something that saved your child's life, we're wanting to remove, you know'. ..It would be really good to have training that would be really good. (p6)

One participant talked about the difficulty managing tube fed children when the main issue was mealtime behaviour or parental anxiety. SLTs do not usually manage these issues. She felt that there was a gap in services around support for these children and their families for mealtime behaviour management. This was due to the lack of psychology services:

.. I don't feel like we work well as a team at all when it is a very behavioural thing. I always refer to psychology but they tend to decline a lot of our referrals. So we're sort of at a lack of service there. (p7)

The SLTs identified that there was also a lack of formal psychological support to help parents work through transitioning their children from tube feeding to oral feeding. The SLTs tried to provide extended support to assist with behavioural issues, but felt stretched because the support required was beyond the scope of their training.

Parents seeking intensive support

This section focused on participants' descriptions of gaps in service delivery around intensive support for families who wanted their child's tube removed. Parents found it difficult to do this without intensive support from the SLT and other team members:

And I think she (mother) just found it really hard to listen to the advice and then carry it out when we weren't there and she did actually say herself you know, she asked, could we... can you just come every day and do all the feeding...we are not able to offer that service. So in the end she actually approached one of the Graz therapists from Germany...And he was, there every day for every mealtime you know, really supportive for her. And I think that's what that mother felt she needed, was that support. (p4)

The above participant reported that this mother sought treatment from private therapists overseas to provide intensive assistance over two weeks on a daily basis to help with the transition of her child to oral feeding. The SLT commented that the mother did not feel confident carrying out the advice from the SLT on her own. The SLT felt that this intensive support assisted this family to transition from tube to oral feeding. However, this participant was frustrated at not being able to provide this intensive support for families due to structural constraints:

..With a big caseload it's really hard to allocate really the time to those kids. And they certainly need intensive work and, it's hard to provide that. (p5)

One participant spoke of the positive feedback received from participants in the intensive programme her workplace provided. She reported that the support helped the parents to focus on their child's feeding skills and difficult mealtime behaviours. This ability to focus on these issues allowed the parents to learn to implement new strategies to help their child at mealtimes. There is access to intensive support to transition children to oral feeding in some but not all areas of New Zealand:

It's been really good and I think some of the feedback that I've been hearing is that it's been so good for the families to have intensive input and to really give the parents that mind-set and that constant feedback and to focus on it. And for the parents to really learn and get super on board with it to really learn new strategies and really ramp up their engagement and focus on feeding for two weeks. You know and leave the other kids at home and leave the house chores at home and really focus on, how do we, you know strategise around this. And like okay they're having a tantrum and throwing food like, great what should I do now, and really learn. (p7)

Participants recognised structural constraints in the workplace as an obstacle affecting the success of their clients' transition to oral feeding. The participants' comments indicated that SLTs considered they were well placed to contribute substantially to more effective weaning regimes given appropriate resourcing.

Barriers to family meal culture

Participants highlighted that there was a cultural shift in New Zealand, away from families sitting together through a dedicated mealtime. This informality in mealtime arrangements may work against the normalising of eating routines and rituals for tube fed children:

And the problem with that is with the children we see need to be really engaged in mealtimes in order to develop their oral motor skills and develop their feeding skills and if they're distracted by watching TV or a video then they're not able to you know, to watch and model and learn about eating and learn about the mealtimes. (p4)

The next quote by one participant focused on the barriers that interfere with family mealtimes to such an extent that encouraging some oral feeding at home was too difficult:

The barriers that get in the way is finance for sure for some families, other children... demanding partners, you know. Working, doing all the things that a mum would normally

do becomes really, really tricky when you've got a tube fed child and school. And sometimes oral feeding just doesn't happen at home....So I've got a family where it's been easier, they've said to me it's just easier to just put it down the tube. And it's very hard not to judge but they're right, it is easier to put it down the tube. (p6)

Cultural differences

Participants commented on the difference they observed between cultural groups in terms of their attitudes to tube feeding and including these children in mealtimes. The participants mentioned that Pacific Island cultures had a positive relaxed attitude towards oral feeding. This next comment focused on the difference between Pakeha (NZ European) and Pacific Island mothers in terms of their attitudes towards feeding and family meals:

I think the cultural aspects are really interesting. I find it fascinating... when I started I was told ...you'll probably really never work with Pacific families. And I have rarely worked with Pacific families. And I think that's the whanau thing they're laid back, lots of love and laughter and food and there's not that pushiness you know. Even when I have severely orally aversive kids that I'm discharging home, they're orally feeding pretty quickly...when I've got families from Vanuatu or Samoa...I find it interesting how the very well educated middle class and upper middle class seem to have a lot of tube dependency. You know like it's a lot of Pakeha that I work with you know and they're well educated and...Women much like me with ...good education... and anxiety and you're educated but you're overanalysing and I don't know... I don't know what the answer is there. (p7)

The comment highlighted this participant's perception about differences in Pakeha versus Pacific cultural attitudes towards encouraging oral feeding in their children. This next quote also demonstrates an example of differences between Pakeha and Pacific Island families in terms of modifying food texture so it was easier for children to eat:

Certainly the Island families... they'll often chew the food for them, rather than here's the puree...its different to how you or I would do it but you know they get on with it and I know they will be fine. (p9)

This participant brings to light the untroubled attitude of Pacific Island mothers to modifying food texture for their children when they found it difficult to chew it in its original form. This mother's actions may increase that child's acceptance of that food and consequently increase the child's oral intake. This participant's comments also highlighted the importance of reflective practice when working alongside families of different ethnicities. Although pre-chewing one's child's food might

be a 'foreign' idea initially to the SLT, she appeared to readily embrace the merits of this practice for this family and affirm the families way of adapting food texture to their child's needs.

This next comment emphasised the extra grief these families feel when told their child must not take food orally, due to the cultural importance of food and eating together:

Well for a lot of the Pacific Island families that I work with and to a certain extent the Maori families, food is really important to them and that's how they show their love and nurturing so it's really hard for them to understand that they can't feed their child. .. So they really struggle with that. (p5)

The data highlighted the importance of cultural competence for SLTs; the willingness to locate issues of sustenance outside of medical considerations, and to appreciate the cultural meanings surrounding food and feeding.

Summary

Parental attitude and anxiety was perceived as a contributing factor to tube feeding dependency. Parents were concerned about the weight loss of their child if he/she is weaned. Due to this stress and anxiety parents depend on having their child tube fed and are therefore reluctant to withdraw the tube. The significance of the feeding tube in being life saving for their child and the medicalisation of the maternal role from mother to nurse and carer can be hard for parents to change. Interlinked factors to the above are parental attitude, cultural differences, difficulty at mealtimes, and the need for intensive support by SLTs and psychology during transition from tube to oral feeding. The SLTs in this study acknowledged the need for additional family support around factors related to tube dependency.

Developmental and structural obstacles for school-aged children

According to the participants' accounts, the age of the child was a major contributing factor to tube dependency of children in New Zealand. This is particularly the case when a tube dependent child reaches school age. Participants described a plethora of complex, competing demands that resulted in the normalisation and persistence of tube feeding for some school age children. Family acceptance of the tube; difficulty with implementing intervention to children with tube feeding issues before they go to school; lack of funding and pressure to service a large caseload are some of the factors reported to be associated with older children remaining tube dependent.

Normalisation of tube feeding by school age

A major issue according to the participants was that when children continue to be tube fed after 5 years of age tube feeding becomes normalised by both the parents and those who work with the children on a daily basis. Five participants suggested that normalisation of tube feeding is reinforced rather than challenged in the special education setting. This attitude of normalisation towards tube feeding may contribute to children remaining tube dependent.

The following participant reported that when tube feeding is broached with the family it is difficult for families to accept when children are infants or pre-school age. However, when the children reach school age tube feeding has become part of the family routine. Therefore, normalising this routine may make it harder to transition the child from the tube to oral feeding, even when they no longer require tube feeding:

At pre-school it's much harder to get them on tube feeding... Then they are not interested in getting them off anymore, like no one is jumping, there are not many people jumping at school age to get their child off tube feeding. (p1)

And I think as well when kids get to five, six or eight.. I've seen these tube at eight, and families by that point have really normalised stuff and they reach a point of acceptance of this is the way it is. But, it's those ones that sit in special schools and this is what happens. Any intervention is great but then you get to schooling and everything changes. (p6)

The data above highlighted that these families' have limited capacity to adapt to the different needs of their children, as they get older. This results in SLTs having little influence about tube weaning once the children reaches school age.

The increase in medically fragile non-funded children for child development caseloads

A significant theme highlighted by all participants was that prolonged tube feeding was exacerbated by workplace constraints, such as lack of funding and increasing caseloads. Such factors have implications for the adequacy of the interventions for these children. The following participant highlighted that interventions may be compromised because of the increasing number of medically fragile children without disability funding. These children cannot access some services that support

tube weaning. This issue increases the number of tube fed children on their caseloads and takes time away from children with disability funding who are medically stable.

This participant also stressed another problem with the New Zealand health service and education service in relation to the Ongoing Resourcing Scheme (ORS). Children get this funding if they meet a certain criteria for support with learning:

“There is no funding for those children within this service, so, that is definitely having an impact on our caseloads and waiting lists. .. Often those children need to be seen quite urgently because they are medically fragile and there is a safety risk. And that means that often our children with disabilities have to wait longer and get less of a service because we're having to deal with those medically fragile children. So that's definitely an issue. The other issue is children over five, there isn't actually any funding for children over five who don't have ORS funding. (p4)

The way in which children are categorised for funding affects the type and amount of professional services they receive. Classification can marginalise those in need for more intensive input.

The next participants' comments highlighted reports that service delivery becomes fragmented because of institutional policies and referral processes, as the child gets older. She also comments on the increase in referrals of children with complex needs:

Yes, so I certainly struggle with having a large case load and these kids (personal health) seem to be taking up more and more of my time. And for a lot of the kids they're not actually funded for us because they're personal health kids and not disability kids. .. We're kind of getting squeezed more and more to try and provide a greater service for a larger population and a more intensive service as well. But yeah, it's really hard to provide that. (p5)

During the interviews, most participants spoke in depth and with considerable emotion about the professional stress they experienced managing complex caseloads equitably:

*The funding for paediatric and SLT services is horrific and you can quote me on that. My other paediatric colleague and I went to a meeting with Ministry of Education and we sat around the table with the Ministry of Education SLTs. There were around forty of them and there were two of us and my colleague is part time and we see all the children and more, because through cleft clinic we see **NZ regional city**, a massive region and we are expected to somehow provide a good service. I don't think people understand that we could actually be saving the DHB money if we got this right in the beginning. (p8)*

Participants spoke of the frustration they experienced. They perceived that social services were not keeping abreast of medical advancements. Therefore, with the increased survival rate of children, their long-term quality of life was compromised because of inadequate service provision:

You know, a lot of children are surviving with more complex medical issues., I think it's great that these children, are surviving and they're able to go home with these feeding tubes but it has had a big impact on service provision and unfortunately there hasn't been any extra funding to support these children in the community which is a real... a real problem. (p4)

Yes, yes. I know that from talking with [local child health team]...that they've had, referrals for eating, drinking, swallowing increasing exponentially, we've gone from 80 students to 100 plus in the 2 years I've been here (special school), and we are having children arriving every day, that doesn't mean they're tube dependent, or fed by tube, but some are. (p9)

These two participants worked in different settings, (p4 health and p9 special school) and with different age groups. Both reported an increase in the number of tube fed children on their caseloads without the additional supports for this service.

Change of service delivery as child gets older:

The majority of participants spoke about the change of the service delivery model for older children. Once a child turns three years old, home based interventions change to clinic/outpatient services:

...when they finally get to a point where they are medically stable to be able to start doing tube weaning we can only see them in a clinic, which really isn't the best environment (p5).

And then also we've got the kids that because we see them until the age of three at home and then once they turn three they get sent to other services and we can only offer clinic appointments for them. (p4)

It's harder to get the child out of school and bring to clinic. And if you go to school the mum's not there or the main carer, you need to have the main carer there. (p6)

These three participants discussed the disadvantages of not being able to see the children in their homes to assess their skills or provide therapy. The inability to see the child was problematic for the SLTs because it is important to assess the child holistically in the home environment. Furthermore, home visits help to promote/provide feeding plans to assist generalisation of these new feeding skills to different contexts. It is important that the changes made at school transfer to the home environment to allow these feeding skills to develop.

Summary

From the SLTs' perspective age of the tube fed child, particularly when a child reaches school age, appears to contribute to tube feeding dependency. This is due to the normalisation of tube feeding by parents and parental resistance to change by school age. Current service delivery models appear to reinforce the status quo of maintenance of tube feeding in children. The reports of these participants showed complex interlinked factors that contributed to children remaining tube fed. Such factors included funding; classification of children's health difficulties and associated funding; no changes to support health teams working with increasing numbers of tube fed children; parental adjustment needs and limited service delivery options. Therefore, tube feeding of children most likely persists because of the impact of the above factors and the inability to work intensively with them in their pre-school years.

Service Delivery Issues

All participants spoke about service delivery issues affecting the SLTs and other members of the MDT in how they manage tube fed and tube dependent children. Participants spoke particularly on the influence of historic and philosophical ways of working in health and education on service delivery. Service delivery issues were broken down into a number of subthemes: Philosophical differences in the Education setting by prioritising communication needs of the child instead of their feeding needs; the confidence of education support staff in schools to support the oral feeding skills of children in that setting; and the "small voice" of the SLT in a wider MDT as they try to advocate for the needs of tube fed children. Finally, the lack of joint planning and communication across the MDT for transitioning children from tube to oral feeding all contribute to persistent tube feeding.

The impact of philosophical differences between health and education services for tube dependent children

There appears to be tensions between the SLTs who work in health and those who work in education in New Zealand about their role for children with swallowing and feeding difficulties. The next participant focused on the major philosophical tensions between health and education and where the SLT fits:

There's this split in SLT society of education and health, I think that's a biggie. So people in education think that.., health needs to do the feeding and they do the communication, which I totally disagree with because I think we're all educated to do something around feeding. (p1)

The next quote by the same participant highlighted her perceptions around the impact of the philosophical stance that exists in the education setting that affects the tube dependent child. She

reported that SLTs and other MDT members working in the education setting did not want to work directly with swallowing and feeding issues. An argument used is that working with swallowing, feeding issues are new to this setting, and is unsafe territory for clinicians. This way of thinking around working with swallowing and feeding issues have stemmed from the historic ways of working in the past where education and communication needs of the child have been prioritised.

Sometimes the risks I think are being.., hyped up more than they need to be and then people are just getting scared to go there. It's not just the funding, it's also the culture, it's the fear of touching [feeding], it is the environment, the people in the environment, families or team members who are just not that keen on change..., you know can we try oral? "Oh my gosh they're coughing, we'll never try it again!" (p1)

This participant described a situation where her colleague 'covered' her fear of working with tube fed children by focusing on the large number of children on her caseload who required intervention for their communication difficulties:

She's very smart but she's insecure about feeding because she doesn't have enough kids with feeding problems. She's very capable but she's got so many kids with communication problems she'll just prioritise them ... Whereas I think if she would have less kids on her case load and would be able to have a look at someone else in the special unit and to have a look at someone who is doing this work at another unit where they have to do a lot of kids with feeding problems...get some confidence or you know, get supervision from someone who can help you through the process of doing an assessment. (p1)

This next participant is an experienced clinician who has worked with feeding and swallowing difficulties for many years. She now works in a special school environment and reflected on the change she found from working with pre-schoolers in the health setting to working in the school. She found that due to the priorities of the school, she did not have the acquiescence of the school to spend time with the parents to find out what their child's feeding skills are like at home

Something that I experience in terms of working in a school, that is different for me is I have to work out the tension of working with families, in comparison to when I worked at child health centres and at .., and even in special education services, if I needed to I could easily spend a lot of time talking with parents. But I find there's quite a lot of pressure to see students and be one of the school staff members, so I don't necessarily give myself permission to spend a lot of time with parents, finding out in depth, what happens for parents with tube feeding. (p9)

The participant described a significant tension about the differences between education and health services in New Zealand. She described the change from children moving from health to education at school age where meeting with parents regularly to determine what is happening at home in terms of feeding is not part of the education culture. It appears that the focus of their role shifts to contact time with students in the classroom setting rather than a holistic view of the client and the family. The SLTs highlighted that the education setting did not prioritise oral feeding.

The impact of the philosophical differences between health and education and the related issues for the SLTs working in these services emerged from the data. SLTs working for Ministry of Education have traditionally focused on managing the communication needs of children and not their feeding problems. On the other hand, SLTs who work in health manage both the feeding and the communication difficulties of the child. The difficulty of children with tube dependency going into an Education setting is that feeding issues are not a prioritised

Confidence of Education support staff skills to support oral feeding

Participants expressed concern that some parents have to go to school to feed their child when they reach school age. Due to an educational rather than a holistic focus on the child the feeding needs of the child are not prioritised. The SLTs reported that due to this focus on education, support staff were not given enough support to orally feed children in their care. Due to this lack of support and prioritisation, these staff members were not confident to feed children by mouth preferring to tube feed as it was deemed safer:

..Mum comes in to orally feed her child because the school refused to do it. ..With all the training and everything the teacher aid said "I don't get paid enough if anything goes wrong"...But that's the way things are going now, kids with special needs are being put in mainstream school. The teacher aides don't have training, they don't have the regular updating. And tube feeding is much safer in their eyes.

...They don't see feeding as part of their therapy in the school, they just see it in the light of changing a nappy or changing a pad. It's like, well this is something that has to get done. Right cool, let's get on to something else. (p6)

The comments above show the impact of educational support staff confidence on parental decision-making. Parents' desire to have their children mainstreamed may serve to reinforce prolonged tube feeding.

Challenges for the SLT to advocate for tube dependent children

The majority of participants discussed the challenges they faced advocating for tube dependent children as part of the wider MDT. The SLTs felt that they were the only profession that could advocate to transition children to oral feeding but were not being encouraged to by their MDT. This perceived lack of interest by the MDT may be the result of compartmentalisation of care. Each profession may have its own focus and challenges in their workplace and therefore a holistic vision for their patients' care is not developed.

...you've got so many kids on your caseload and these kids take time. And no-one is pushing for it. You know, if I sit down and don't do anything no-one will change the situation. And it's often, I think that's another thing with us having these huge caseloads you're running around like mad in your job and then deciding to push for this when no-one's actually waiting for it to happen. It's easier not to I think, for a lot of people. (p1)

In the next quote, a participant described the challenges advocating for tube fed children, as they are often the only SLT on the MDT. If their views appeared to contradict those of their colleagues in the MDT they feared that their professional opinions were reframed as a personality issue:

So we have 1.8 FTE [full time equivalent] for paediatric SLT. And that means we have a very small voice on the teams and it also means that when we are saying but what about this, but what about this, but what about this then you become the annoying person, because there is only one voice quite often. (p8)

As with health, the SLTs working in schools had similar experiences of feeling that they were the only profession advocating encouraging oral feeding in children. The SLTs spoke consistently about the professional isolation they experienced managing tube fed children in the education setting:

And people then just start accepting things that they are the way they are and then if you go in and try and change them it's like, well this is the way it is and it works so why would we change it.... And I used to feel very lonely in the school. (p6)

The SLTs experienced professional disempowerment in both the health and education settings due to being a small voice in relation to the wider MDT. The SLTs felt other professionals side-lined their point of view as their professional agenda dominated decision-making.

Lack of joint planning and communication across the MDT for the tube fed child

Most participants commented on the lack of integrated planning and communication among the MDT members. Issues that arose in the data were from the lack of communication between the SLT and medical colleagues in the NICU setting, affecting feeding plans. In addition, MDT members being located in different geographical locations subsequently affecting clear goal setting between professionals.

The following participant talked about a communication issue with a medical colleague in the NICU. She expressed her frustration because another team member had disregarded her feeding plan for the infant. This infant tired easily and experienced poor coordination with oral feeding. This SLT wanted the baby to experience a short feed to help the infant establish oral feeding skills. However, her colleague changed the slow flow teat the SLT had given to provide a safer more organised yet slower pace of feed to a fast flow teat. This teat by being fast flowing caused the infant to lose control of the liquid leading to oxygen desaturation during the feed and giving a negative experience to the infant and family:

But you know there's, the frustrating thing is that when you start off feeding, and you say ok I don't want you to do more than 10 minutes because they're getting puffed out and tired, and then you'll get somebody who comes in on the nightshift and decides well you know this is taking far too long, we'll just put it on a faster flow teat and the whole thing goes to custard.. Instead of people following the plan. People don't read, the notes or the feeding plan, it is frustrating. (p10)

The participants spoke about the problem of communication oversights or exclusions among the MDT members because the members of MDT are located in different geographical locations and/or work for different teams. These oversights meant the SLT did not know about medical appointments or did not have enough information from medical files and therefore were not present at meetings to raise concerns that were happening in the school setting. The next participant worked in a school and said that it was common for her not to know about medical appointments or subsequent changes made to her students' feeding plans. This was due to the doctor coordinating these meetings being located at the local hospital. She felt it would be useful if she were also present at these appointments to carry out the advice in the school setting for a more cohesive service for that child. However, she reported that she was not informed of these appointments.

Sometimes it still happens now that you would be the last to know that there is something happening in terms of medical appointments. (p2)

This next participant commented about communication issues also due to geography of the MDT within the same health service. She commented that as the nursing and child development team were not located close to each other in their hospital setting, this caused limited communication between health professionals. This lack of communication, affected future planning to help transition children to oral feeding. Thus leading to missed opportunities in the office environment to arrange joint visits and discuss cases:

And because we don't all work in one team, so anyone who is tube fed will have a dietitian and will have home care nursing but they are in a separate department and we do, we meet together every two weeks and do as much as we can to work together but we are all so busy and so stretched that things do fall over sometimes..we come at things from different perspectives. ..So I come very much from a developmental perspective and they come very much from a medical perspective and sometimes it lines up really well and other times it just doesn't. ... I mean only in my experience, it feels less related to medical conditions and more related to planning. (p8)

The participants indicated that the type of service delivery model might result in communication breakdowns between MDT members; contributing to the lack of a shared vision surrounding 'care packages' for these complex children resulting in less than ideal outcomes.

Planning for transition to oral feeding in the future:

Some participants stressed the importance of future planning for the child's transition to oral feeding. Particularly, planning for a PEG insertion in infancy could be one way to combat the negative side effects of long term NGT feeding. This next comment specifically relates to the need to start planning to change from a NGT to a PEG tube if the child requires tube feeding for more than 3 months:

From NICU if they know [the infant] in the long term is going to need a nasogastric tube, they then need to start discussing with the family, referral for PEG at that point. Maybe not necessarily making the referral for a PEG but at least having that conversation and starting the family thinking about it. (p5)

Another participant indicated that if a tube fed child is unsafe to feed orally, it is important to begin oral feeding from the start even if only minimal amounts of liquid can be given by mouth. She perceived that this would make 'weaning' from the feeding tube much easier. She highlighted the importance of introducing oral feeding with the introduction of the tube:

It's very important and that's a very important principle to me, that when we place a tube we plan how it's going to come out. So we will be working with the parents and reviewing the child every so often and make sure that the parents are normalising things for the child... For instance, a lot of children may be able to eat a bit of solids...To get in there at six months to start establishing solid foods. Because when you've got those things in place, the weaning is a breeze. It's those kids that go under the radar that come to you when they're two years old and then it's a huge disaster. (p3)

The participants emphasised that part of their contribution to the MDT and to families and children was to ensure that the goal of encouraging oral feeding was kept in view and worked towards.

Summary

The SLTs considered that they had a pivotal role in working to assist tube dependent children to transition fully or partially to oral feeding. However, their ability to be influential was often stymied by organisational constraints. These constraints include the impact of philosophical differences across service providers, the lack of prioritisation of feeding in the education setting, resulting in education support staff lacking confidence to feed children in their care orally. Communication issues affecting cohesive care of MDT for the tube fed child and the need for better planning to transition from the tube at time of insertion.

Tube feeding and negative sequelae

The majority of participants spoke about the feeding tube itself and the negative issues associated with it. These included the impact of limited appetite, the negative aspects of prolonged NGT feeding including sensory defensiveness and aversion associated with the NGT. In addition, pain and the vomiting and pain associated with the tube feeding. The participants identified these as factors contributing to persistent tube feeding.

Lack of appetite

Participants mentioned the role of appetite as an obstacle to oral feeding, particularly for infants born prematurely:

I find with ex prems [infants born prematurely but now discharged home] if that tube's been in... like if it doesn't get out in that first six months post discharge, it seems to be really hard to ever get out and I think maybe that's because they've just never... Like one of the ex prems that I've got, she's never had a hunger drive. (p5)

The child will not feed if they don't have appetite. Driven by appetite has been shown in research in breastfeeding. (p3)

That is probably one of the big issues if they've always been tube fed then they haven't necessarily learnt to respond to the hunger cues or they've never actually had a chance to develop hunger if they've had continuous feeds. And to know when they're full as well, so that can be really tricky if... yeah obviously if you're not hungry then you're not going to want to eat. (p4)

I really struggle, I've got a child that I'm seeing at the moment that I'm really struggling with because I've known her since she was on her on NICU and now I'm seeing her in the community two and a half years later and since NICU she's never been interested in feeding. (p5)

This next participant mentioned that a group of children with metabolic conditions had particular difficulty transitioning from tube to oral feeding because they needed frequent feeding during the day:

We have also seen a few children with metabolic conditions as well and they can be really tricky to work with and often it is actually really difficult for us to work with those children because of their medical condition they need to be fed frequently throughout the day. So we can't sort of mess with their tube feeding regime too much. (p4)

There can be obstacles to creating opportunities for these babies to develop an appetite; a point expanded on in the next sub theme below.

The participants commented on the issue of reduced appetite for infants born prematurely. These next remarks from two participants working in the health setting, related the difficulty that premature infants have in developing an appetite due to the scheduled feeds prescribed by the medical professionals. The purpose of scheduled feeding is to improve weight gain and facilitate growth. However, these scheduled feeds did not assist in developing the hunger drive in infants. If the infants do not develop a hunger drive this may result in continued tube feeding when the baby is discharged:

..but even from our new born intensive care unit it is very much we follow this algorithm and we are not planning for getting them off this tube or.... Yeah, it is kind of crisis care all the way along and then it stops. (p8)

Well I suppose you know you think, everybody should have the desire to eat, but then if you go back to prem babies, I don't think that they do have that desire, you know that's just from overall experience, and that they're tube fed for so long, that they have a full tummy and

then they go home, and you know you're trying to transition to breast or bottle, and it then fails so they get a tube again, and so they haven't actually had to work for it. (p10)

To ensure that the baby develops and thrives, the focus of care in the acute hospital setting is on growth and weight gain even when the baby's medical condition is stable. This medical focus marginalises attention to longer-term developmental goals.

A recurring point raised by participants during their interviews was the problem of oral sensory defensiveness or aversion, which is the emotional response by the child to sensory input to the oral facial region. These children will usually avoid food differing in textures and tastes, and avoid mouthing toys and teeth brushing. This affects their ability to accept foods orally, and in addition, the volumes needed to sustain nutrition. The participants reported that wherever possible there is the need to work proactively to minimise this risk. In the next commentaries, the participants remark that having the NGT in for a prolonged period seemed to lead to aversion for the child:

So she left the ward with a nasogastric tube because she was having difficulty with tolerating volumes and subsequently became unwell multiple times. ...Was nil by mouth for a period of time and now is extremely averse and.., sensory averse to anything kind of around her face. (p5)

This next participant described a child on her caseload who was discharged home with a PEG tube instead of a NGT. This infant transitioned to oral feeding quickly. The participant speculated that it was possible that the type of feeding tube played a part in this rapid transition to oral feeding. She noted that the insertion of the PEG might have limited the prolonged negative oral and sensory experiences of the NGT:

She actually came out with a gastrostomy tube because she didn't tolerate the nasogastric tube so they had to the gastrostomy while she was in hospital...I do wonder if the fact that she had a gastrostomy rather than a NGT tube played a part because there is some evidence to suggest that children are more likely to develop an oral aversion if they've had a NGT tube.. with things going in and out of their noses and nasty experiences around their face, tape causing rashes on their face and having a tube down the back of their throat, all of that I think plays a part. (p4)

In the next comment, the participant highlighted the traumatic experience of having the NGT reinserted every 6 weeks or more if the tube was pulled out or was dislodged. She also mentioned how the child was more willing to join in meals and oral feeding when the NGT was removed:

The nasogastric tubes getting inserted... in [part of major NZ city] we do it every 6 to 8 weeks and then there are the ones [infants and children] that just want to pull it out all the time as well... I've watched the nurse put the nasogastric tube back down and I've been traumatised by how awful it is...Once they've had their gastrostomy we've seen a complete change in their demeanour and their ability to sit and tolerate food around them. (p5)

The participants appeared well aware that the type of tube, particularly NGT, might have an effect on tube dependency. They reported that NGTs might increase tube dependency because of the negative oral and sensory associations that the child may develop with its insertion.

Recurrent vomiting was another aversive experience for the infants that participants felt affected transition from tube to oral feeding. This could possibly prolong tube feeding for these children. Participants spoke with frustration about how management techniques inadvertently prolong tube feeding. The comment below is about how the tube feed was given via continuous feeds (a small amount given every 2-5 minutes) because of repeated vomiting:

..And then with the way they're throwing up all the time, they tend to drip feed them, so they never have that hunger drive, and I think that probably is the root cause as to why a lot of children stay on tubes for so long. (p10)

This participant spoke of her experiences of seeing or hearing about multiple children whose persistent vomiting ceased once, the tube was removed:

I know all the medical team will say that the tube does not cause vomiting but so many families tell me about the vomiting with tube feeds and multiple families see it resolved when the tube comes out. And it's like these mucus vomits from what I hear about all the time. And we've just got to the point now where we call it a functional vomiting issue because there's no anatomical cause, there's no medical cause but we've got these tube fed kids that vomit all the time...I've seen it with all types of tubes. I don't know if it's something to do with the sudden delivery of milk into the stomach...or being predominantly milk fed. (p7)

The participants spoke about the frustrations clinicians and families experienced because of the persistent vomiting related to tube dependency.

Pain

Participants mentioned pain, in particular gastroesophageal pain as a factor that may prolong tube feeding. Pain management may be necessary to help transition children to oral feeding. The comment below tells how this participant through her own evidence-based practice explored the use of analgesia to help transition children from the tube to oral feeding:

It's certainly been interesting reading all of the research around it and looking at a lot of the research that's saying, using pain medication to help with tube weaning. (p5)

This same participant described pain caused by gastroesophageal reflux (GOR) affecting infants and children who are typically developing who were not tube fed. However, the consequence of this pain often led to food refusal and subsequently tube feeding:

Reflux I think is another big issue... With a lot of these kids I wonder if there is a significant reflux component that's causing them pain and discomfort that they can't express to us and is that what's causing the refusal and...Because we've got a couple of otherwise typically developing kids that have been refusing and we can't figure out why. And then it's escalated from.. parents getting stressed about not being able to feed child and yeah, all of that's developed. The initial food refusal .., we've not really known why it's come about. ..I think that's definitely an untapped area. (p5)

Summary

From the participants accounts the negative sequelae related to tube feeding may contribute to prolonged tube feeding and subsequent tube dependence. These include negative oral and sensory experiences associated with the type of tube, lack of appetite, the timing of the intervention, vomiting, and pain management strategies.

Chapter Summary

This chapter presented the findings from the semi-structured interviews. Four main themes and twenty sub-themes evolved from the transcripts of the interviews. Participants' reports of their experiences working with tube dependent children revealed the complex nature of managing these children and supporting their families from infancy to school age. Threaded throughout the themes were strategies and outcomes from experiences that informed the participants' professional practice.

In the next chapter, the main findings from both the survey and interviews will be integrated for discussion. Following the discussion are the conclusions, implications and practical applications of the results. In addition, the limitations of the study and directions for future research will be presented.

Chapter 6 - Discussion and Conclusions

There is growing concern by health professionals about children remaining tube fed when there appears to be no medical reason for continued tube feeding. These are children have medical conditions and developmental potential that should allow them to transition to eating and drinking orally. To assist in understanding why children remain tube fed the aim of this study was to obtain the SLT perspective about the factors that contributed to paediatric tube feeding dependency in New Zealand. The importance of obtaining the SLT perspective is that SLTs are one of the key professional groups to manage long-term tube feeding and weaning.

There were two parts to this study. The first part was an online survey of forty-three SLTs involved with tube fed children. The aim of the survey was to identify the factors that SLTs considered as contributing to tube-feeding dependency in children. In the second part, ten participants from the survey were interviewed. The purpose of the interviews was to help build on, add depth to, and explain the initial survey results.

Both sets of results are integrated in this final chapter, with results from both parts of the study grouped together and combined into two Meta themes and ten sub themes. This chapter will discuss these two main themes and sub themes derived from the data in regards to existing literature. The first theme is *medicalisation being a root cause of tube feeding dependency*. Sub-themes include medical emphasis on weight gain; parents and caregivers influence whether a child remains tube dependent, parents giving misleading information to maintain tube feeding and prolonged NGT feeding. This leads to the second theme of the *fragmentation of the tube fed child's continuity of care*. Sub-themes include; the need for planning tube withdrawal at the time of insertion, insufficient clinical time, funding issues, the need for intensive service at the time of tube weaning, clinician confidence in the education setting and the normalisation of tube feeding by school age. These themes and sub-themes influence tube feeding dependency in New Zealand, according to the perspective of SLTs. This chapter will conclude with practical applications based on the study findings, limitations of the study and directions for future research.

Medicalisation as a root cause of tube feeding dependency

Medicalisation is a powerful 'lens' through which health professionals and lay people make sense of health, illness, and embodiment. Traditionally, medicalisation refers to the rise in the use of medical definitions and frameworks to interpret an expanding array of human behaviours and conditions (Kanieski, 2010). Medicalisation also means that perspectives of medical staff may take precedence over the views of other health professionals. Medical practitioners are trained to observe people's behaviour, classify individuals as sick or healthy, and to treat the sick. From the

study, SLTs highlighted that the medical staff in the NICU drove decision-making and this medical dominance has continued for years beyond the initial crisis time when the tube is first inserted. This medical perspective focuses on the medical condition of the child rather than their developmental potential.

The data from the interview participants revealed a professional tension between medical staff and SLTs in the hospital environment. SLTs wanted to advocate for the child and the family regarding feeding development but were often in conflict with their medical colleagues. The data revealed that some SLTs faced a difficulty whether to advocate or to be compliant in this MDT setting. SLTs would prioritise teaching parents about feeding cues and readiness, whereas their medical colleagues prioritised the growth and weight gain of the child above their developmental potential for oral feeding. The SLTs' goals for the tube fed infants were for them to experience success with short oral feeds. Observing the infants' for clinical signs of fatigue and physiological stress cues affecting the infant's suck-swallow-breathe coordination (Arvedson & Brodsky, 2002; Dodrill, 2015). Tube feeding would then follow their oral feeding so that the infant would receive the remaining volume of food. The medical goals of the MDT, on the other hand, were to feed the child a set amount of nutrition via the tube at regular intervals or via mouth but not taking into account, the infant's physiological stress cues (Shaker, 2013). The SLTs in this study perceived that prioritising feeding to promote weight gain affected the development of feeding skills in these tube fed children

This prioritisation of weight gain over developmental potential on the NICU could be related to what Shaker (2013) describes as the cue based versus volume driven feeding approaches in the NICU. A volume driven culture has existed on the NICU for many years (Shaker, 2013). This culture is based on the belief that the 'better nurse' was the one who could increase the milk intake of the infant. If a NICU unit has a volume driven approach their priority will be for the infant to increase oral intake regardless of the physiological stress experienced by the infant. This approach does not take into account the quality of the infant's oral feeding skill and feeding development (Shaker). A consequence of the volume drive approach is the possibility that the tube fed child may experience negative associations with oral feeding, appetite dysregulation and reduced oral intake of food at feed/mealtimes. This may often lead to children requiring prolonged tube feeding due to the negative feeding experiences they have endured early in infancy.

These negative feeding experiences can lead to the child refusing oral feeding, as they get older. The survey results showed that the SLTs perceived reduced oral intake of food at mealtimes as a cause of tube feeding dependency. This finding was supported by the comments from the interview participants. A possible reason for the reduced oral intake of food is the inability of tube

fed infants and children to establish appetites due to rigid tube feeding schedules leading to prolonged tube feeding (Mason et al., 2005). Two participants commented on their experience in the NICU saying that all tube fed babies were given a set amount of liquid with no plan to transition them to oral feeding and that these infants did not show any hunger cues. Another interviewee commented that tube fed infants often did not make the connection between taking the breast or bottle and feeling satiated because they were tube fed since birth. This lack of connections between oral feeding and satiety is concerning because researchers have found that children who have limited oral intake have difficulty developing the oral sensorimotor skills needed for eating (Clark, 2003; Edwards, Bruce, Mousa, Lyman, Cocjin, Dean et al., 2016; Shepperd, 2008). Shepperd (2008) comments further that if sufficient practice time, task repetitions, and appropriate environmental supports are not provided for oral feeding, the child may have delayed development or acquire dysfunctional movement patterns for feeding. This impact on development may lead to persistent tube feeding and consequently tube feeding dependence.

Findings from this study and the literature agree that the influence of prioritising weight gain at the expense of feeding development from an early age may be a factor that appears to influence prolonged tube feeding and consequently tube feeding dependency. This is due to limited oral intake leading to oral motor and feeding development being stymied (Edwards et al.2016). Developmental potential is influenced by short-term medical goals being prioritised. The opportunities for the child to experience positive and safe oral feeding/exploration experiences in infancy are not encouraged even though they are vital to help prevent reduced oral intake in the future or tube dependency.

The influence of medicalisation as a root cause of tube feeding dependency leads to the next sub theme of parents and caregivers influencing whether the child remains tube dependent. The data from both the survey and the interviews suggest that parents and caregivers are focused on weight gain and less on developmental goals due to the medicalisation of their child in early infancy. With such a focus, both survey and interview participants commented that parents and caregivers have become reliant on the tube and this reliance was often preventing the child to be tube weaned.

Byars et al. (2003) reported from their tube weaning study that parental involvement is essential for the child to transition successfully to oral feeding. There must be a strong commitment and readiness from the family in order for weaning to be successful. The SLTs in this study also agreed that parents and caregivers played a pivotal role in influencing the outcome of tube withdrawal interventions for tube dependent children. This study found that the SLTs perceived that parents were motivated to wean their children from their feeding tubes. However, although motivated the process of transitioning their children to oral feeding was

difficult for some parents, due to their long-term reliance on the tube for their child's nutrition and wellbeing from early infancy. The SLTs acknowledged that multiple factors including anxiety about their child's weight loss, stressful mealtime behaviours, and subsequent reliance on the tube made tube weaning a lesser priority compared, both for their child, and for their family as a whole.

The role of the parents in influencing whether a child remains tube dependent or is weaned successfully was a major finding from this study. The SLTs perceived that parental anxiety about their child's potential weight loss affected tube weaning. Parents have faced a harrowing journey since their children's infancy, having faced life and death situations. Therefore, every gram increase of weight signified progress and greater chances of survival for their child. Eight participants interviewed reported that parental anxiety about possible weight loss and lack of nutrition given to their children caused parents to rely on tube feeding. The participants' reported that parents were reliant on fixed tube feeding schedules because nutritional intake was guaranteed for their children. Six interview participants commented that in their clinical assessment parents found it difficult to step away from the 'parachute' and the 'crutch' of the tube. One participant commented on a mother who would 'top up' her child with tube feeding even when he/she had received sufficient food from oral feeding. These actions most likely related to heightened anxiety due to a prolonged period being concerned about their child's health status, subsequently leading to persistent tube feeding for some children.

Maternal anxiety may affect the parent-child interactions during feeding and ultimately the feeding relationship (Hewetson & Singh, 2009; Wilken, 2012). Moreover parental anxiety regarding weight loss is well known and has ramifications for the child transitioning to oral feeding in the future (Dunitz-Scheer et al., 2011; Edwards et al., 2016; Hewetson & Singh, 2009; Pederson et al., 2004; Wilken; 2012; Wright, 2013b; Wright et al., 2011). This anxiety and the subsequent reliance on the tube appear to stem from the volume driven culture of the NICU unit (Shaker, 2013), where weight gain is prioritised over development of the child. This medical dominance stemming from the NICU affects care of the child as weight loss is expected during weaning from the tube. However, mothers are either not aware of this and/or fear weight loss and their role in that. Rather than seeing it as part of the weaning/ transition process, due to the influence of medicalisation. This can result in persistent tube feeding due to maternal anxiety about weight loss.

There are similar findings regarding medicalisation influencing parental decision making in the Health literature related to the effect of childhood illness on family life. Due to a child's medical condition, researchers have argued that family life becomes medicalised (Apple, 2006; Kanieski, 2010). In order to prevent further illness or loss of life, medical and health professionals have guided parents and caregivers in decision making related to nutrition and weight maintenance to

prevent hospitalisation and further illness of their tube fed child. This occurs through continued medicalisation though further monitoring of the child as they grow through clinic or home visits. This preventative practice by medical and health professionals is defined as surveillance medicine (Armstrong, 1995). Surveillance medicine is concerned with bringing disease under control through the identification of risk factors for disease. Under surveillance medicine, the attempt to distinguish between health and illness has been transformed into a search for risk factors that are most likely associated with the development of illness (Kanieski, 2010). Kanieski argued that surveillance medicine creates obligations for parents. That is, when a child is sick, often the mother is subject to the regulation and judgement of medical authorities on why the child is sick. A finding from the interview data highlighted this. The participants remarked that some mothers gave false information to health professionals about their child's oral feeding volumes, to prevent the possibility of tube withdrawal. Another participant described how a mother gave the SLT and the community nurse different information about the amounts of fluid the child received from the tube because she wanted the child to remain tube fed.

This parental strategy of withholding or altering information is similar to findings in nursing research that revealed lying by the mother and concealing information due to their anxiety about being powerless regarding medical decision making regarding their child's care (Shepherd, 2011; Wilson, 2001). These qualitative studies involved interviewing home care nurses about their experiences home visiting families of sick children. Wilson (2001) found in her study found that 100% (5) of the participants reported the mothers withholding information from them regarding their children's weight loss. Shepherd (2011) reported similar findings. Ten home visiting child health nurses commented on mothers masking their feelings; not wanting to be seen as not managing even with a child with high health needs. Although nursing literature, these studies demonstrate the impact that medicalisation has on not only the child but on the mother and family. The lying by parents to health professionals about their child or the care of their child seems to come from the mother's anxiety and the feeling of disempowerment due to their child's illness. This disempowerment begins in infancy and continues into childhood as part of the medical dominance over their child's condition of being tube fed. Kanieski (2010) argued that there is heightened pressure on parents (particularly mothers) to take action to avoid risk to their child's health and are morally compelled to work to reduce this risk. Therefore, under Kanieski's argument a mother of a tube fed child would see weight loss as a major risk factor and consequently take personal responsibility for ensuring their child does not lose weight.

The consequence of medicalisation for the tube fed child is that short term based medical decisions are made rather than the MDT and family having a shared holistic vision and care plan for

the child, which includes tube weaning. Both parents and professionals are more concerned with avoiding risk than advocating for children's developmental potential. This leads to the final sub theme; the impact of prolonged NGT feeding on tube feeding dependency in children.

Long term NGT feeding was seen as a factor preventing transition to oral feeding by SLTs in this study. The comments from the interviewed SLTs suggested that the type of feeding tube used to feed the children contributed to persistent tube feeding. The SLTs perceived that children with NGTs inserted for prolonged periods were more likely to become tube feeding dependent. Reasons for this tube dependency are the symptoms the children acquired, for example the development of oral aversion to food, exacerbated vomiting, and pain in the nasopharyngeal region when NGTs were used for prolonged periods. This oral aversion due to prolonged NGT feeding is consistent with findings in the literature regarding the negative side effects of prolonged NGT feeding (Avitsland et al., 2013; Hawdon et al., 2000, Mason et al., 2005). It seems clear from the literature and the findings that prolonged NGT feeding needs to be seriously considered and advocated for by the MDT.

The interview participants discussed the change of demeanour of children once a PEG tube was inserted and NGT feeding ceased. This observed change in their demeanour supports the additional comments of one participant who reported the transition to oral feeding occurred quickly when a PEG tube was used instead of an NGT for feeding. The SLT speculated that the type of tube played a part in this quick transition to oral feeding due to the child not having the negative experiences of the NGT for a prolonged period. It appears that from the SLT perspective prolonged use of NGTs causes secondary difficulties including pain with swallowing, consequently reducing oral intake for the child, and contributing to delayed transition to oral feeding. The effects on swallowing because of the pain and trauma it causes to the pharynx and oesophagus due to long-term use of an NGT were also found by Skuse,1993; Meyer, Palmer & Heyman, 1993; Mason et al., 2005). The SLTs' perceptions in this study about the effects of prolonged NGT use are similar to these findings.

The interviewees perceived that the reinsertion of the NGT every few weeks caused pain and consequently distressed the children. The SLTs' perceptions are similar to findings by Babl, Mandrawa, O'Sullivan and Crellin (2008). They obtained the perceptions of medical and nursing staff about pain and distress in young children having emergency medical procedures, for example NGT insertion, intramuscular injection and lumbar puncture. These medical personnel perceived that NGT insertion distressed the children the most. In addition, Hawdon et al. (2000) reported from their prospective study of the effect the NGT has on establishing oral feeding in early infancy. They found that NGT placement delayed establishment of oral feeding due to the NGT exacerbating respiratory and cardiac distress and causing oral aversion in neonates. Regular reinsertion of NGTs

from the literature and the participants' accounts has negative consequences for the child's feeding development due to the aversive experiences that have to endure with reinsertion. An alternative to reinserting NGTs is to have PEG tube is placed. This is discussed next.

Feeding via PEG tubes has been suggested as an alternative to NGT feeding (Avitsland et al., 2013). Avitsland et al. (2013) obtained parents' perceptions of the effects of PEG tube placement for their previous NGT fed children. They found at 18 months post PEG tube placement that child and parent satisfaction with the change to PEG feeding as well as parent-child interaction at mealtimes improved significantly. Current European guidelines state that if tube feeding appears to exceed 4 to 6 weeks then that is an indication for PEG tube insertion (ESPGHAN, 2010). These findings by Avitsland et al. and ESPGHAN are similar to interview data suggesting that NGTs, although important for children to receive nutrition quickly, should avoid prolonged use. It appears clear from the data and the literature that if a child requires tube feeding for more than four to six weeks then PEG insertion needs to be planned by the MDT.

Another finding by Avitsland et al. (2013) is consistent with a major finding from the study on regular vomiting from prolonged NGT use; and the effect of PEG insertion in decreasing the occurrence of this in tube fed children. A major finding in the study was the identification by the SLTS that regular vomiting by tube fed children is a likely contributing factor to tube feeding dependency. Avitsland et al. found that as well as PEG tube insertion improving parent child interaction at mealtimes; parents and caregivers also perceived that vomiting decreased and oral intake increased with the insertion of the PEG tube and the cessation of NGT feeding. This was also a key theme found in the interview data: That vomiting ceased in a number of children post removal of the NGT. Therefore, vomiting may be a side effect of having an NGT and a factor influencing prolonged tube feeding.

It is unclear whether feeding via a PEG tube decreased the vomiting of tube dependent children. However, from the reported information in this study, vomiting and food aversion caused by prolonged NGT feeding appears to contribute to tube feeding dependency. The short-term medical emphasis by health professionals was perceived by the SLTS in the study to be contributing to prolonged NGT use and consequently tube feeding dependency due to the aversive symptoms the NGT causes. Greater advocacy for early NGT removal is required by SLTs and members of the MDT to avoid the possibility of the child developing aversive sequelae described above.

The SLTs in this study perceived that medicalisation was possibly a root cause for tube feeding dependency. This biomedical focus on the child starts in the NICU environment and progresses through the child's care. As a result, goal planning and care plans are influenced, affecting the child and family's continuity of care as they transition through different services. This

leads to the second theme to be discussed, where medicalisation leads to *fragmentation of the care pathway for the tube fed child*. Early on, a medicalised approach ensures children's survival. As children become more stable medically, competing goals become more evident. However, the dominant influence of the medical model is already well established and appears to continue to drive care decisions. Data clearly demonstrate that where care decisions and goals diversify, medical goals continue to be privileged. SLTs, who are socialised into the medical model, appear to find it challenging to contradict medical goals and take up a strongly voiced advocacy role.

Fragmentation of the care pathway for the tube fed child

The influence of the medical model leads to the next discussion meta theme; Fragmentation of the care pathway or discontinuity of care. Reid, Haggerty and McKendry (2002) describe continuity as the degree to which a series of discrete events are experienced as coherent, connected, and consistent with the patient's needs over time. They maintain that two core elements are essential for continuity: That care should be experienced as smooth and coordinated by the client, and is provided over time. This study found that the SLTs perceived that the continuity of care of the tube fed child was fragmented. This was highlighted by the survey results and interview data, including a lack of planning and integration amongst the MDT working with in and across services, insufficient clinical time with increasing caseloads and lack of resourcing despite the increasing numbers of tube fed children. The continuity of the tube fed child's care was also found to be fragmented at transition points for the tube fed child. This fragmentation occurred when children transferred to education services at three years of age and again when entering school. In addition, upon entering school, the SLTs perceived that decreased clinician confidence amongst the SLTs and MDT has led to the normalisation of tube feeding by school age.

Researchers report that the age of the child and the degree of exposure to oral feeding experiences may affect prognosis for successful tube weaning (Duniz-Scheer et al., 2007; Edwards et al. 2016; Ishizaki et al, 2013; Marinshek et al., 2014; Wright, 2011). Dunitz-Scheer et al. (2007) emphasised the need for that the MDT to establish clear goals for the child from initial tube insertion to the final transition to oral feeding. However, although this may be in the best interests of the tube fed and tube dependent child interview participants commented on how difficult it was to develop collaborative plans across both the health and education settings. One participant in the health setting remarked that her MDT were in different departments and could only meet every few weeks. This participant also reported that as well as not being co-located, that she and her colleagues also came from different philosophical perspectives. The participant came from a developmental perspective and her nursing and dietetic colleagues from a medical perspective,

further fragmenting potentially holistic MDT care plans. This was due to a lack of joint visitation to families and differing goals for the child. This SLT believed that tube dependency was related more to planning issues of the MDT than the child's medical condition. Another participant, in the education setting reported that she often received no communication about upcoming appointments with her client's medical team at the local district health board. This participant remarked that the medical professional often changed the children's feeding plans with accompanying collegial correspondence arriving weeks after the appointment.

A combined MDT approach across a service continuum is considered the best approach for tube fed children (Edwards et al., 2016). However, the service continuum for a tube fed child is complex spanning both health and education services, general practice, paediatrics and specialist medical services. For many teams in New Zealand providing continuity of care proves challenging due to differing locations, administration, and perspectives, influencing prolonged tube feeding.

Three interview participants highlighted another example of fragmentation occurring in the pre-school years for tube dependent children. They spoke of the change from home based intervention to a clinic/outpatient monitoring service from the health team once a child turned three years of age. The reason for this change is due to the child transferring to other services for communication and educational needs and only clinic appointments could now be accessed from the health SLT. The participants were frustrated about and commented on the effect this has on both the SLTs and the child and family. As well as the child having two SLTs to see with different priorities; they reported that it was harder for families to attend clinic appointments and difficult for them to implement changes advised in the clinic to the home environment.

Similarities to what these SLTs experienced were also found in current Health literature. Empirical research and reviews identified ineffective communication pathways, restricted information transfer and limited collaboration between professionals in Child Health Family Services in Australia (Eronen, Caabretto & Pincombe, 2011; Jeyendra, Rajadurai, Cajnmugam, Trieu, Nair et al., 2013; Psaila, Schmied, Fowler & Kruske, 2014; Schmied, Mills, Kruske, Kemp, Fowler and Homer, 2010). These researchers found that these difficulties contributed to the discontinuity of care for children with complex needs. These ineffective ways of working caused by service constraints highlighted in both health and education settings by the participants were found to contribute to lack of cohesion and vision by the MDT for tube fed and tube dependent children. This leads to a major finding in the study; that of insufficient clinical time to address tube feeding and weaning issues. Insufficient time may be a factor contributing to tube feeding dependency.

The SLTs in the survey agreed that insufficient time to help children transition from tube to oral feeding contributed to prolonged tube feeding. In addition, this major theme emerged from the

interview participants from both the health and education settings. Lack of time, increased clinical caseloads, and the change of service delivery models were described by interview participants as factors influencing prolonged tube feeding. The participants described fragmentation in the pre-school years for tube fed children due to many of them not being eligible for disability funding as they were categorised as having personal health not disability issues.

This medical categorisation has affected the service provision by the MDT for the tube fed child. The child health teams were still required to manage their increased caseload with no supported funding; this was also identified in the school setting highlighted by two interview participants. One interviewee from the community health setting reported that children with feeding tubes with associated health fragility were increasing with no change in resourcing for the team. This lack of funding had a significant impact on service provision, as they were not able to employ more staff to assist with managing the increasing caseload. Another participant from the education setting commented that in her regional area children with eating, drinking and swallowing issues, including tube dependency were increasing. Her colleagues at the local DHB have reported infant and pre-school referrals rising exponentially and at her school setting, they have seen an increase of eighty to one-hundred plus children in two years of which many were tube fed and tube dependent. The interview participants spoke about how difficult it was to advocate for tube weaning in the school setting. The participants commented that staff are so busy that they have to give priority to their particular professional emphasis, so that combined goal setting was challenging.

One explanation for more continued tube feeding in school age children could be their ineligibility for ORS funding for assistance in school (Ministry of Education, 2016). This funding is given to children who meet a certain criteria for support with learning which many tube dependent children are not eligible for as they may have only mild to moderate learning needs. This lack of funding means that there is no dedicated teacher aide funds available to assist in feeding, and therefore parents are forced to compromise; to have their child schooled, which will limit their oral feeding development.

The limited funding available, not only for the children, but also for resources appears to be influencing the transition rate of school age children. Jelleyman (2013) found that shortages of SLTs in parts of New Zealand meant that the practice of tube weaning was limited. This issue is not unique to New Zealand, as previously reported by Wright (2013a), and more research is needed to find ways to assist tube fed children reach their oral feeding potential, despite resourcing constraints.

Another reason for this lack of time to assist parents with tube weaning could be the result of care rationing in the health and education services. Care rationing is defined as the withholding

of or the failure of health and education professionals to carry out necessary duties of care for patients/clients due to a lack of resources and insufficient clinical time (Carryer, 2014; Carryer, Diers, McCloskey & Wilson, 2011; Kalisch, Landstrom & Williams, 2009; Schubert, Glass, Clarke, Aiken, Schaffert-Witvliet & De Geest, 2008). Care rationing can include reduced staffing and/or reduced skill mix in wards or departments, therefore increasing caseloads, which will reduce time available to assist the weaning of tube fed children. Care rationing also refers to clinicians having reduced time to see patients/clients. The possible effect of care rationing was seen through interview participants' comments about insufficient resources, one being time. The issue of insufficient time appeared to be similar across work settings and age groups for the SLTs who participated in the interviews. Insufficient clinical time was also a major finding identified by the SLTs in the survey. Tube weaning is a time-intensive activity, often requiring significant travel time, and significant collaboration with the family and the MDT team.

Care rationing may affect the use of rapid weaning interventions due to insufficient clinical time. Research has shown that rapid weaning interventions using intensive input and time from health professionals have been more successful in terms of transition time, more so than gradual weaning interventions. Transition time for rapid weaning tends to be weeks compared to gradual weaning that takes months or years (Brown et al., 2013; Byars et al., 2003; Ishizaki et al., 2013; Kindermann et al., 2008; Marinschek et al., 2014; Trabi, 2010; Wilken et al., 2013). Insufficient resources and time reported in the findings particularly in the health setting seems likely to influence the use of rapid weaning interventions.

The interview participants agreed that a lot of time was needed to support children to transition from tube to oral feeding. Four interview participants commented that there was a need for intensive input if children were to be transitioned to oral feeding to support families adequately in the process. Intensive service is the process when the MDT supports children and families daily or at least three to five days a week for approximately three weeks to wean them onto oral feeding. Two participants spoke about their team's experience of helping children transition to oral feeding in their homes and as inpatients. They reported that the intensive service allowed parents to focus and adapt quickly to implement strategies encouraging their child's feeding.

This increased professional support appears to be necessary to assist families with this process and aid faster transition to oral feeding. Although an example of best practice in terms of time and efficiency, intensive intervention is not utilised in health and education settings, due to insufficient clinical time and resources; influencing the potential for tube withdrawal. Subsequently, the SLTs in education services and schools are now faced with the challenge of managing tube

dependent children where traditionally their focus was on the children's education and communication needs.

This difficulty for health teams to progress with tube withdrawal in the pre-school years appears to be causing an increase in the number of tube dependent children entering school. Challenging the traditional ways of working for SLTs and the wider MDT in which education and communication have been the focus of service delivery. Both the survey and interview participants emphasised the need for more training and support with tube weaning. A major theme that emerged from the interview data were the participants' concerns about their SLT colleagues and the MDT attempting to manage children with tube feeding in an education setting. Their concerns expressed related to the lack of confidence of the clinicians in their skills to manage tube weaning and encouraging oral feeding potential at school. The SLTs interviewed drew attention to the fact that less confident SLT colleagues in an educational setting tended to focus on the communication skills of the children rather than their feeding problems. Although this focus was justified as a workload issue, the participants believed that the workload argument was used to obscure their colleagues' lack of confidence in managing the weaning process for these children.

Interview participants reported that teaching assistants were also not confident feeding children in mainstream schools. This lack of confidence in feeding children also has ramifications for the parents. Two interview participants described mothers coming to school to feed their children because the therapy assistants were unwilling to feed them due to the length of time the feeding took and their lack of training. Even though these children had ORS funding for additional support, it was not provided for feeding.

The difficulty in managing tube fed children in schools, as reported by interview participants is consistent with other research findings. Bailey Stoner, Angell, Fetzer (2008) found there were challenges adapting dysphagia and feeding practices traditionally used in a medical setting to the educational setting in the United States of America. Even though there were current American guidelines for treating feeding and swallowing in schools. Bailey and colleagues found that SLTs had difficulty adapting their practice in the school setting. The reasons for this were that SLTs in schools were fearful of students' choking and/or having aspiration events; their lack of training to support children adequately; and being supported to administratively to do swallowing and feeding work. That is ensuring SLTs have adequate clinical time to plan assessments and feeding plans, to meet with the MDT and the medical specialists. Current ASHA guidelines state that clinicians and other professionals in the school system must be prepared to recognise signs and symptoms of dysphagia and be prepared to provide appropriate interventions for dysphagia, including assistance with the transition to oral feedings if appropriate (ASHA, 2007a; Lefton-Grief & Arvedson, 2008). Changing

practice may be a challenge for SLTs and members of the MDT to focus on dysphagia and feeding when historically the focus has been on communication difficulties and their work setting cannot yet provide them with adequate support to do this work.

With the change in focus of practice for SLTs, there is now the need for additional training for these professionals to identify the children who have the potential to be weaned or transitioned slowly. More research about the effects of support and training for school staff and professionals to encourage oral feeding potential is required. The SLTs in the study perceived that a potential consequence of not addressing clinician confidence and changing practice is normalisation of tube feeding by school age. This was an interesting finding in the study and will be discussed next.

A strong theme that developed through the interviews was the acceptance by parents and school staff that the tube feeding of some children was normal. This normalisation of tube feeding occurred at school age even though the child had the potential to eat orally. Two participants described the difficulty they had advocating for tube weaning in educational settings. One participant experienced with tube feeding and tube weaning, reported that once she started working in an education setting she found it challenging to meet with parents to ask about feeding at home. She considered that there was a definite philosophical shift between pre-school and school services about supporting families with feeding. This participant emphasised the importance of working directly with parents especially in regards to supporting oral feeding in the home. However, this was not deemed as important now the child was at school. Another interviewee commented that families and school staff had normalised tube feeding for children aged seven and eight and saw it now as part of the child and weaning or trying any sort of oral feeding were not prioritised.

Psaila et al. (2014) found in their study regarding a lack of continuity in Child and Family Health in Australia, that each professional group was primarily concerned with the management of care within the confines of their own service as opposed to management continuity between services or professional groups. Psaila and colleagues also found that discontinuity of care was most evident at transition points in the child's care.

Similarly, as Psaila and colleagues found, management continuity is fragmented for the tube fed child. This is seen through significant transition points in their care; from leaving NICU to the community, from health to education in their pre-school years and finally to school services, continuity of care is fragmented. This is due to a break down in the management continuity between services and professionals; caused by service constraints, historic ways of working and funding. This was seen in the findings regarding insufficient clinical time. This was a significant

response in the survey as well as the interview data as well as the lack of planning by the MDT commented by participants in the interviews.

This leads to the impact on the tube dependent child's continuity of care in the pre-school years and transition to school; leading to the majority of tube dependent children in New Zealand as school aged. Resourcing and service constraints in the pre-school years affect the opportunity for health teams to tube wean, meaning more children are going to school still tube fed. As a result, management continuity between health and education services is fragmented. There needs to be a better transition process for children between services to ensure a cohesive transfer between teams when children change services. There also has to be more support and training offered to SLTs and the wider MDT in the education service to support them to manage tube fed children in schools.

Significance of Study

SLTs have a pivotal role within the MDT to assist and advocate for the families of children who are navigating the complexities of tube management and tube weaning. The accounts from highly experienced practitioners about the complex web of clinical, psychological, cultural, personal, socio-political and economic factors contributing to tube feeding dependency has not been explored previously. Identification of factors that potentially prolong tube feeding may assist in the development of strategies to prevent tube dependency and expedite tube weaning. This study is timely, as the Ministry of Health in New Zealand has established a National Clinical Network to set up clear guidelines on managing children who are tube fed and tube dependent to allow these children to reach their oral feeding potential. The findings of this study can provide some input to assist in creating policies, changing philosophies and historic ways of working. This includes the creation of more cohesive management plans that prioritise the needs of both mother/caregiver and child to support families towards transition. In addition, understanding and identifying key factors causing tube feeding dependence can help to develop prevention strategies and education for clinicians working in this field.

Implications of findings

The most concerning issue that arose from the study is that medical decision making from NICU drives care decisions often not considering developmental potential. Subsequently leading to most feeding tube dependent children are of school age and that tube feeding is becoming normalised in the education setting. The study has also found that SLTs were very concerned that insufficient clinical time and resource constraints especially in the pre-school years affected this population. More resources should be prioritised for pre-school aged children to develop their oral

feeding potential and transition to oral feeding in the optimal developmental period of the first three years of life.

The consequence of not prioritising resources to tube dependent children of pre-school age is that there will be an increasing amount of tube fed children transferring to the education environment. SLTs and other professionals in education services have not traditionally practised intervention work to encourage oral feeding for this population. The SLTs and assistants in the school sector are not sufficiently trained nor do they have the expertise to help their students and their families, leading to normalisation of tube feeding in schools. Education and training to support these professionals is needed to assist these children to reach their oral feeding potential.

Practical Applications: Prevention Strategies

From the study five key strategies that should be considered to prevent feeding tube dependency are:

Cue based feeding in NICU

A cue based feeding approach as described by Shaker (2013), that focuses on the infants' quality of feeding rather than the quantity the infant receives appears to be a beneficial management strategy. This management approach aims to help the mother read her child's cues for feeding and help establish a feeding relationship in the homeostasis phase of development. This helps the mother focus on the feeding development of her child, preventing her from adopting a carer role of ensuring set feeding volumes for her child. Changing the NICU philosophy of volume feeding to cue based feeding sets precedence for the child's management in the community. This suggests an increased likelihood of weaning the child at an earlier age thereby, increasing quality of life for the child and family.

Planning to remove the tube from the time of insertion

After insertion of a feeding tube, it is important that the MDT set goals at this point for the transition of the child from the tube to oral feeding. Dunitz-Scheer et al. (2007) also recommended this proactive planning. Such a plan can support oral feeding development and increase parental awareness of the importance of the development of feeding milestones. As with cue based feeding, this increases the likelihood of weaning the child earlier because they have developed appropriate oral sensory motor skills.

Encourage oral exploration and scheduled mealtimes

Education regarding the importance of oral exploration and scheduled mealtimes to assist with the development of feeding skills for parents should be part of the role of the SLT. Increasing parents' awareness of these factors, allows them to prepare for the possibility of transition from tube to oral feeding at the appropriate time. This is relevant even if their child cannot take any food

or fluid orally. Furthermore, allowing the child to mouth toys and non-food items will help support oral skill development, which is a precursor to the development of eating.

The first three years of a child's life is the critical time to encourage exploration and establish independent oral feeding). Consistent messages from the MDT about the importance of moving to oral feeding to parents may support this transition better. This means that parents will consider the need for oral feeding and manage small fluctuations in weight that in the early stages of care had a significant effect on the child's wellbeing. An early message to parents needs to be consistent across services and professionals to help them engage with different feeding practices. Oral exploration activities should occur even when the child is tube fed for swallowing safety and/or for nutritional requirements for a prolonged period. Furthermore, if tube feeding occurs over a prolonged period of time PEG tube placement requires consideration. (Arvedson, 1997; Arvedson & Brodsky, 2002; Dunitz-Scheer et al., 2007; Dunitz-Scheer et al., 2011; Illingworth & Lister, 1964

Limit NGT time

Prolonged placement of NGTs causes discomfort and altered sensory perception in tube fed children. These changes in sensory perception lead to oral aversion and food refusal (Mason et al., 2005). NGTs may also exacerbate GOR and vomiting for tube fed children, which can also lead to food refusal (Hawdon et al., 2000). Forward planning to remove NGTs and replace them with PEG tubes is required when the outlook for tube feeding is for a substantial amount of time (ESPGHAN, 2010).

Support for professionals to encourage oral feeding potential

Interview participants highlighted the need for training professionals across health, and particularly education settings to transition tube fed children and/or to encourage oral feeding potential. School staff and professionals should be made aware of the time it takes to encourage oral feeding and to consequently transition to oral feeding. This particularly relates to school aged children and those that have developmental and/or medical issues. Research into gradual weaning interventions in outpatient and school settings supports this (Ishizaki et al., 2013; Mc Kirdy et al., 2008; Wright, 2013b).

Support from mental health professionals such as psychologists, to address parent- child interactions and challenging mealtime behaviours was lacking according to the SLTs. This study has found that parents and caregivers significantly influence whether children remain tube dependent. Therefore, these professionals should be part of the MDTs to support parents through the transition process if behavioural issues and reduced parent child interaction at mealtimes is a barrier to oral feeding.

Limitations of study

The findings of the study must be considered in the context of a number of limitations. There were some methodological issues with the research. The Northern MUHEC requested the interview questions as part of the ethics application. Therefore, these questions were not developed based solely on the results of the survey. According to the principles of sequential explanatory design, subsequent ethical approval is required for interview questions after the survey data has been analysed (Creswell & Plano Clarke, 2011). Another limitation of the study is that the participants were not purposefully selected for the interview phase. This was due to ensure the participants' identities remained confidential. Therefore the strength of the link between both phases may be weaker, than if the interview participants were selected to highlight specific results from the survey (Creswell & Plano Clark, 2011). Therefore, the results should be interpreted with caution.

This study only included SLTs working in New Zealand. Although a small number of participants were involved in the study it is representative of SLTs working in the specialist field of paediatric feeding and swallowing in New Zealand. This study only provided the perspectives of SLTs about contributing factors to feeding tube dependency. Perspectives of other professionals were not taken into account. Social desirability bias appears to have been a result for the differences in perceptions between the survey and the interview data about age as a contributing factor to tube feeding dependency. Therefore, the findings on age must be interpreted with caution and cannot be extrapolated to all tube dependent children over the age of five.

Directions for future research

This study has provided a greater understanding of the factors contributing to paediatric tube feeding dependency. Identifying the contributing factors can direct future research. Further investigation using qualitative methodology to gather information from families on how to best support them with encouraging oral feeding and tube withdrawal is important. Developing a screening tool that identifies factors that indicate which children may be at risk of tube dependency would help MDTs plan better cohesive goals to prevent development and/or seek assistance to counteract identified issues. Focus groups of multidisciplinary professionals working with tube fed children may be the best way to achieve this. For SLTs, clinical research into the relationship between oral sensory motor activities and the development of appropriate feeding skills would be a valuable contribution.

Final Thoughts

This study was important because it has revealed factors that may affect tube dependency in children. It highlights the need to provide improved services for children who are tube fed. Several implications that indicated both children and the parents of tube dependent children need to be given cohesive MDT plans and goals to encourage weaning. Although weaning is developmentally ideal, an early and ongoing biomedical focus on weight gain continued to affect long-term goals for transitioning to oral feeding. The goals of the members of the MDT were not shared or consistent in terms of priorities for the child. This lack of a shared vision led to parents receiving competing and conflicting messages prolonging tube feeding.

This study is one of the first to examine the phenomenon of tube feeding dependency from the perspective of the SLT. Overall, the outcome of the study suggests both the children and the parents need comprehensive and cohesive plans and goals to encourage transitioning to oral feeding.

Most importantly, these results suggest that there is a need for greater advocacy for these children; to bring about change in service delivery and training of professionals to support these children from infancy to school age.

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Appendix A: Information sheet for survey



Speech-language therapists' perspectives on paediatric tube feeding in New Zealand

• INFORMATION SHEET – INVITATION TO PARTICIPATE IN A SURVEY

Researcher(s) Introduction

This project is being carried out by Emily Jones, a master's student in the Speech-Language Therapy program at Massey University, Auckland, under the supervision of Associate Professor Helen Southwood and Dr. Catherine Cook. Emily is currently employed part-time as a Clinical Educator by Massey University.

Project Description and Invitation

The aim of this study is to gain insight into speech-language therapist's perspectives on tube feeding for children aged 0-16 in New Zealand. We know that speech-language therapists play a major role in working with these children however, there is very little information regarding speech-language therapists' perspectives on tube feeding.

This is a two-part project. The first part involves a **survey** of Speech-language therapists (SLTs) working with tube dependent children to identify therapy and management strategies as well as the challenges they face in managing the tube fed child. The second part involves an **interview** to obtain more detailed information on the topics outlined above. If you choose to interview details will be provided about the interview process.

I would be very grateful if you would consider participating in one or both parts of the project.

Participant Identification and Recruitment

I am recruiting speech-language therapists who

- a) Work with tube fed children in health, education and private sectors.
- b) Do not have tube fed children on their caseload at present but have worked with this population in the last 5 years.

Project Procedures

The **survey** component of the project involves completing an online survey. There will be questions about tube feeding and managing this in your work as a speech-language therapist in New Zealand. The survey can be completed at a time that is convenient to you and will take approximately 15 minutes to complete. **After completion of the survey there is no obligation to participate in the interview.**

Project Contacts

If you think you might be interested in being part of this project, you can complete the survey online by following the link. The survey is anonymous. By choosing to complete the survey, it is assumed that you consent to your responses being used in this research project

<https://www.surveymonkey.com/s/tubefedkids/SLT>.

If you have any questions relating to the project, please call Emily Jones on **021530047** or Associate Professor Helen Southwood **414 0800 Ext. 43533**.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 15/001. If you have any concerns about the conduct of this research, please contact Andrew Chrystall, Acting Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43317, email humanethicsnorth@massey.ac.nz

Thank you for considering this project.

- This information sheet is for you to keep



Emily Jones
Masters Student
Speech-Language Therapy Program
Institute of Education
Massey University

Appendix B: Information sheet for interview component

Speech-language therapists' perspectives on paediatric tube feeding in New Zealand

INFORMATION SHEET – INVITATION TO PARTICIPATE IN AN INTERVIEW

You have indicated that you are interested in participating in an interview. This involves an interview that will last about 60 minutes. You will be given a choice of the time and location for the interview. Interviews will be digitally recorded for later transcription. You will have an opportunity to read and approve the transcripts after the interview. If you live more than 200km away from Auckland, the interview will most likely take place via telephone, or Skype.

All of the information that you provide to the researchers will be kept confidential and will be stored in a locked office at Massey University. Only the researcher and her supervisors will have access to the information.

When the project is finished, you will receive a copy of the key findings of the study. The results of the study may be published in journals or presented at conferences; however the information will not include the names of any participant.

The data from this study will be secured in a locked cabinet and locked office for 5 years following the completion of the final publication. When disposed of, the University confidential waste service will be used for printed materials, and audiotapes will be wiped.

You will be compensated for your time with a \$25 Westfield voucher.

Participant's Rights

If you decide to participate, you have the right to:

- Decline to answer any particular question.
- Withdraw from the study by **August, 2015** prior to the commencement of data analysis and have any data pertaining to you destroyed.
- Ask any questions about the study at any time during participation.
- Provide information on the understanding that your name will not be used.
- Ask for the audio recorder to be turned off at any time.

If you have any questions relating to the project, please call Emily Jones on **021530047** or Associate Professor Helen Southwood **414 0800 Ext. 43533**.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 15/001. If you have any concerns about the conduct of this research, please contact Dr Andrew Chrystall, Acting Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43317 email humanethicsnorth@massey.ac.nz



Emily Jones
Masters Student
Speech-Language Therapy Program
Institute of Education
Massey University

Appendix C: Interview consent form



Speech-language therapists' perspectives on paediatric tube feeding in New Zealand.

PARTICIPANT CONSENT FORM – INDIVIDUAL INTERVIEWS

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have the transcript of the interview sent to me to approve before analysis.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:

.....

Date:

.....

Full Name - printed

.....

Appendix D: Interview Schedule for Semi structured Interviews

Interview Schedule for Semi structured interviews:

Thank you for participating in the 2nd phase of the study. I am Interested in looking at factors that contribute to tube dependency in children from an SLT perspective.

I am interested about your professional perspective in regards to tube dependency in children in New Zealand.

Tube dependence is defined as an unintended result of long term tube feeding in infants and children. These are infants and children who remain tube fed although their medical condition and developmental potential would allow them to transition to eating and drinking by mouth

SLT perspective of working in a multidisciplinary team (MDT) for tube dependent children

- 1) Tell me about your work setting and the multi-disciplinary team you work with when assisting children who are, or may become tube dependent?
- 2) In your clinical experience, do any particular memories stand out that shaped your practice working with tube dependent children and if so, why?
- 3) How does the MDT work with tube fed children?

SLT perspective on working with families who have a tube dependent child

- 4) How does the family manage long term intervention for their child?
- 5) What is involved in managing the aspects of tube feeding issues when working with parents and children?
- 6) What factors worked well?
- 7) Can you think of a time when intervention did not go well?
- 8) How do you manage these needs?
- 9) Does the MDT have strategies to manage these issues?

SLT perspective on medical issues impacting tube dependency

- 11) In your experience what are the particular medical conditions that are challenging when working with tube fed children?
- 12) If you were educating a new SLT student about steps to avoid tube dependency what would be the key points you would discuss?
- 13) Are there any broader service allocation and funding issues that you perceive contribute to tube dependency?
- 14) As an SLT working with tube feeding, you are engaged in multiple relationships – with the MDT, parents, children and whanau. Is there anything else you think is important to tell me about this context that you consider may have some bearing on the development of tube dependency?

Please provide the following information:

- 15) How long have you been working as an SLT?
- 16) Age
- 17) Work setting (health, school, education, private)
- 18) Work contract
- 19) In the course of your work, approximately how many children have you seen who have been tube dependent?

N.B. Given that there are a relatively small number of speech-language therapists in New Zealand, please discuss with the researcher any concerns that you have about the provision of points 17-21 that might compromise your anonymity if published. Any potentially identifying material will be withdrawn. You may decline to provide any of the above information if you have concerns.

Appendix E: Transcribers Confidentiality Agreement



Speech-language therapists' perspectives on paediatric tube feeding in New Zealand.

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I John Edward Charles Rott (Full Name - printed; agree to transcribe the recordings provided to me

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project

Signature:

John Rott

Date:

18/09/2015

Appendix F: Human Ethics Approval



MASSEY UNIVERSITY ALBANY

31 March 2015

Emily Jones
Institute of Education
Massey University
Albany

Dear Emily Jones

HUMAN ETHICS APPROVAL APPLICATION – MUHECN 15/001

Factors that contribute to paediatric tube feeding dependence in New Zealand: The speech-Language Therapist's perspective

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a re-approval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Andrew Chrystall
Acting Chair
Human Ethics Committee: Northern

cc Associate Professor Helen Southwood
Institute of Education
Albany Campus

Dr Catherine Cook
School of Nursing
Albany Campus

Tū Kurenga
ki Pihirihiri

Research Ethics Office
Private Bag 102 304, Auckland, 0745 New Zealand Telephone +64 9 711 0800 fax 43273 humanethicsnrm@massey.ac.nz

Appendix G: Survey Questions

Instructions

This survey asks about your experiences and opinions regarding children who are tube fed. The survey will take about 10 to 15 minutes to complete.

1. Please state your qualification.

*2. Are you currently practising as a speech-language therapist in New Zealand?

- yes
- no

***3. How many years have you been practising as a Speech-Language Therapist in New Zealand**

- first year
- 1-2
- 3-5
- 6-10
- 10-20
- 20+

***4. State your employment contract.**

- Full time
- part time
- self employed
- not currently employed, (e.g. parental leave)

***5. What location do you work in?**

- Rural
- Urban
- Mixed

***6. Which best describes your current main workplace (tick multiple boxes if necessary)**

- DHB
- MOE
- Other non-government organization, e.g. CCS Disability Action
- Special School
- ACC Provider
- Private practice

Other (please specify)

***7. What age groups of children do you work with: (tick as many as apply)**

- 0-1 yrs
- 1-3yrs
- 3-5yrs
- 5-14
- 15+

8. Do you currently have children on your caseload who are tube fed?

- Yes
- No
- Unsure

9. How many tube fed children are on your caseload?

- none
- 1
- 2
- 3
- 4
- 5+

10. On average how many children are on your current caseload.

- 1-10
- 11-20
- 21 - 30
- 31- 40
- 41-50
- 50+

11. If you currently have no children who are tube fed on your caseload, in the past 5 years have you worked with any children who were tube fed?

- yes
- no

12. Please indicate the number of children fed via the methods listed below.

nasogastric tube	<input type="text"/>
nasal jejunal tube	<input type="text"/>
gastrostomy/mickey button	<input type="text"/>
orogastric tube	<input type="text"/>
Other	<input type="text"/>

***13. Identify other professionals that you work with or have worked with in the past to manage tube fed children.**

(tick as may as apply)

- Nurse
- GP
- Paediatrician
- other medical doctor, e.g. gastroenterologist
- Dietitian
- Visiting Neurodevelopmental Therapist
- Occupational Therapist
- Physiotherapist
- Lactation Consultant
- Mental health professional (psychologist)
- SENCO
- Teacher
- Teacher aid
- Specialist teacher (teacher of the deaf, visual support teacher)
- Speech-language therapist from another provider
- Early intervention teacher
- Education support worker
- Other (please specify)

14. What kind of professional and learning and development have you had in tube feeding? (check all that apply)

- Undergraduate coursework
- Graduate coursework
- In-service programs
- Conferences/seminars
- Professional materials
- Assistance from other professionals
- Assistance from parents
- Self directed learning (e.g. reading books, journal articles)
- Online learning (e.g. blogs, participation in forums, websites)
- Supervision
- Personal experience
- none at all

Other (please specify)

Beliefs about tube feeding

Please check the response that most closely represents your current view for each of the following questions on paediatric tube feeding.

*** 15. How significant is the management of a child's tube feeding in relation to your overall management of that child?**

Very significant

significant

Moderately significant

Of little significance

not significant

*** 16. How frequently would you spend addressing tube feeding issues with your client and the client's family?**

Very Frequently

Frequently

Occasionally

Rarely

Never

*** 17. How prepared do you feel to address tube feeding issues in the context of your speech-language therapy sessions?**

Very prepared

prepared

OK

not prepared

Not at all prepared

Beliefs on feeding tube dependency

Please give your opinion on the following statements regarding feeding tube dependency.

Feeding tube dependency is described as the unintended result of long term tube feeding in infants and young children who remain tube fed despite having the potential to eat and drink by mouth.

18. I am experienced working with tube dependent children.

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

Please indicate your level of agreement with the following question and sta...

***19. Children are tube dependent due to their medical condition**

Strongly agree Agree Undecided Disagree Strongly disagree

***20. Children are tube dependent due to parental reluctance to transition them to oral feeding.**

Strongly agree Agree Undecided Disagree Strongly disagree

***21. Children are tube dependent because of team reluctance to reduce tube feeds, due to concerns regarding weight loss and impact to growth.**

Strongly agree Agree Undecided Disagree Strongly agree

***22. Children are tube dependent due to the child's negative reaction to oral feeding.**

Strongly agree Agree Undecided Disagree Strongly disagree

***23. Children are tube dependent due to insufficient clinical time to address transitioning from tube to oral feeding.**

Strongly agree Agree Undecided Disagree Strongly disagree

***24. Children are tube dependent due to lack of confidence of the team to attempt transitioning from tube to oral feeding.**

Strongly agree Agree Undecided Disagree Strongly disagree

***25. Children are tube dependent due to having issues with gastro-oesophageal reflux**

Strongly agree Agree Undecided Disagree Strongly disagree

***26. Children are tube dependent due to having regular vomiting episodes.**

Strongly agree Agree Undecided Disagree Strongly disagree

***27. Children are tube dependent due to parental concerns about their child's nutrition.**

Strongly agree Agree Undecided Disagree Strongly disagree

***28. Children are tube dependent because they are now too old to transition to oral feeding, e.g. they are now school age.**

Strongly agree Agree Undecided Disagree Strongly disagree

***29. Children are tube dependent because they are too young to transition to oral feeding, e.g. they are under 12 months of age.**

Strongly agree Agree Undecided Disagree Strongly disagree

***30. Children on my caseload are tube dependent due to fatigue issues during oral feeding.**

Strongly agree Agree Undecided Disagree Strongly disagree

***31. Children are tube dependent because they do not take enough orally at mealtimes.**

Strongly agree Agree Undecided Disagree Strongly disagree

***32. Transitioning tube dependent infants and children from tube to oral feeding is a high priority.**

Strongly agree Agree Undecided Disagree Strongly disagree

***33. I am confident to advocate transition from tube to oral feeding for my clients in my workplace.**

Strongly agree Agree Undecided Disagree Strongly disagree

***34. The team I work with see transitioning children from tube to oral feeding as a high priority.**

Very important Important Moderately important Of little importance Unimportant

***35. Parents/caregivers of tube dependent children are reliant on the feeding tube and reluctant to end tube feeding.**

Strongly Agree Agree Undecided Disagree Strongly disagree

***36. Parents/caregivers of tube dependent children are motivated for tube withdrawal.**

Strongly agree Agree Undecided Disagree Strongly disagree

***37. It is easier to transition children from tube to oral feeding when they are under 1 year of age.**

Strongly agree Agree Undecided Disagree Strongly disagree

***38. Tube dependent children who are 5 years and over are able to transition from tube to oral feeding**

Strongly agree Agree Undecided Disagree Strongly disagree

***39. I require additional training to adequately manage transitioning infants and children from tube to oral feeding.**

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

***40. Additional team training is needed to help transition children from tube to oral feeding.**

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

***41. At what level should this training be provided? Tick all that apply**

- University-undergraduate level
- University-post graduate level
- Short course -Professional groups, e.g. NZSTA
- Conference/seminars
- Assistance from other professionals
- Self-directed learning (e.g. reading books, journal articles)
- Online learning (e.g. google groups, websites)

Other (please specify)

***42. What strategies have you and your team members used to encourage oral feeding whilst tube feeding?**

- Reducing the volume of tube feeds
- Alternating tube and oral feeding
- Oral feeds during the day, tube feeds at night
- Messy food play
- Encouraging sucking or mouth play during tube feeding.
- Sequential oral sensory groups/other feeding interventions
- Mouthing toys/ Encouraging oral play with non-food items.

Other (please specify)

***43. Would you be willing to participate in an individual interview for approximately 1 hour to discuss managing tube fed children? Please indicate whether you will allow permission for the researcher to contact you. The interviews can be done face to face at your workplace, home or at Massey University. If you live more than 200 km away from Auckland the interview will most likely take place, via teleconference, or Skype.**

- yes -you will be directed to a different site to ensure anonymity of your survey responses
- no

Thank you for participating in this survey.

Thank you so much for your time